Title: The Wellbeing of People Living with Dementia and their Carers During the Hospital Discharge Process: A Qualitative Exploration

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Abstract

The hospital discharge process in England has been criticised by several organisations due to the perceived failure to support the physical, emotional, and social wellbeing of people living with dementia and their carers (Alzheimer's Society, 2016). Despite the prioritisation of the term 'wellbeing' in policy documentation, there is limited evidence regarding the definition of wellbeing within the hospital discharge context. Against this background, this thesis presents the findings of a social constructionist, qualitative investigation into the experiences of carers of people living with dementia and clinicians and explores how the term 'wellbeing' is understood by both groups and what factors support wellbeing throughout the process of leaving hospital.

Twenty-four semi-structured interviews with carers of people living with dementia (n=14) and clinicians (n=11) were subjected to thematic analysis (Guest, MacQueen & Namey, 2011), with codes identified from the data. Drawing on the theory of wellbeing outlined by Kitwood and Bredin (1992), an Appreciative Inquiry method (Cooperrider & Whitney, 2005) was utilised to identify changes that could support the wellbeing of carers and people living with dementia.

Carers of people living with dementia frequently felt that their own wellbeing and that of their relatives was not supported during the hospital discharge process. This was especially the case in relation to policy guidance issued during the COVID-19 pandemic. Informal carers and care professionals identified that ensuring agency, personal worth and hope was crucial to defining and ensuring the wellbeing of both carers and people living with dementia during the leaving hospital process. Expert participants identified changes to the focus of the discharge process that would allow the wellbeing of people living with dementia and their carers to be prioritised. There is an urgent requirement for a change in the discharge process leading to assessments and decisions to be reconstructed to focus primarily on wellbeing for carers and people living with dementia.

Dedication

I would like to thank my supervisors for their support throughout the research project and the many changes that took place over 6 years. Thank you to Dr Clare Abley, Professor Joy Adamson and Professor Thomas Scarf for your feedback and insights during the life of this PhD project. I would also like to thank the Economic and Social Research Council for deciding to fund this project and I would like to thank my parents for all their help and support. I don't know that this thesis would exist without your help and the many ways in which you helped me during the pandemic and beyond. I am so grateful to my husband for listening to me talk about the research, the thesis writing process and for helping me always in ways both small and large. Thank you to my little boy Alfie who was born during the life cycle of this PhD and who always makes me smile.

I would especially like to thank the participants of this study for giving up their time during a difficult and stressful period to speak to me about their experiences. I am in awe of your strength and love.

I would like to dedicate this thesis to the victims of COVID 19 and the carers of the victims of COVID 19, many of whom were unable to say goodbye or access their loved ones during this period. I can only admire your strength.

Thank you to my examiner's Dr Marie Poole and Professor John Keady for their insight into the thesis and its final content.

COVID 19 impact statement

I returned from maternity leave in May 2020 when my baby was 9 months old. I was 10 months into the first year of my PhD period at that point. It was a challenging process as childcare bubbles were not permitted. Further to this, my research proposal included ethnographic observations in the hospital setting and my research was in partnership with Newcastle Upon Tyne NHS Foundation Trust. I realised the research method I had chosen would not be achievable in pandemic conditions. Therefore, I was tasked with the challenge of re-writing the research proposal and rethinking my entire project, including recruitment and data collection methods. The process of adapting my research to make it compatible with pandemic conditions and to include the impact of the pandemic within the research project focus took considerable time.

I had to obtain Health Research Authority (HRA) approval, local Newcastle Upon Tyne NHS Foundation Trust Research & Development approval, NHS Research Ethics Committee (REC) approval, NIHR Portfolio access and an NHS research passport. This was due to my research being focused on the hospital context and involving interviews with health and social care professionals and carers in the community. The process of achieving these permissions was time consuming due to delays in the NHS research process caused by the pressures of the pandemic. I began applying for these permissions in August 2020 and finally received all the required permissions, including NHS Research Ethics Committee approval, in February 2021.

On top of these challenges, I had multiple 10 day + self- isolation periods due to contact with people who tested positive for COVID 19. My son also had contact with nursery staff who then tested positive for COVID 19 during January, February, and July 2021. This left my son in self-isolation for 10 days at a time and I often had to care for him, as he could not leave the house for childcare purposes. There were also multiple periods where I would be in self-isolation for up to 48 hours while waiting for the PCR test result. I estimate that I have spent over 60 days in self-isolation since September 2020. I was also restricted to one childcare bubble, in line with government guidance, for the majority of winter 2020/2021. Further to this, we contracted multiple illnesses in 2021 and 2022 owing to the easing of lockdown and the circulation of contractible illnesses.

Implementing interviews with health and social care staff during a pandemic was challenging due to the busy nature of both the NHS and social care systems during the peaks of the pandemic. The NHS suffered considerable staff shortages due to COVID 19 related illness and self- isolation periods. Interviewing carers was also difficult as they were without respite services for over a year. Carers had limited time to schedule an interview when caring full time for an adult with dementia, with extremely restricted support available to them due to social distancing measures. This entailed that the recruitment of both participant groups was very challenging. It was also not possible to speak to those living with dementia due to the pandemic setting. This is reflective of the restraints of the context and reflected upon in the methods and discussion chapters of this thesis.

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Abbreviations

ADL (Activity of Daily Living)

CASP (Critical Appraisal Skills Programme)

CRN (Clinical Research Network)

DH (Department of Health)

DOLS (Deprivation of Liberty Order)

GTN (Glyceryl trinitrate)

ICS (Integrated Care Systems)

ICP (Integrated Care Partnerships)

NHS (National Health Service)

NICE (National Institute for Health and Care Excellence)

NVivo (Qualitative analysis software)

PCR (Polymerase chain reaction)

PICO (Population, Intervention, Comparison, Outcomes)

PPE (Personal Protective Equipment)

PPI (Patient and Participant Input)

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)

R&D (Research and Design)

SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type)

Summary of thesis.

Chapter 1

The introductory chapter situates the thesis in the broader context of what is known about dementia, being a carer for someone with dementia, the experience of the hospital discharge process for a person living with dementia and their carer, and the importance of the topic of wellbeing in the light of the policy context. Through doing so, it identifies the gap in the evidence base that led to the development of research project outlined. The aims, objectives and research questions of the research project are included within this chapter: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

Chapter 2

This chapter outlines the method and findings of the systematic review which aimed to answer the question: What are the experiences of people with dementia, and their carers during the hospital discharge planning process? The search strategy, inclusion and exclusion criteria and data screening process, data extraction and synthesis process are detailed. The experience of patients and carers was synthesised separately. Omissions in the evidence base available are identified. Limitations of the systematic review are also identified.

Chapter 3

In chapter 3, the policy context of the research project is explored through an interpretivist approach to policy review (Bowen, 2009; Cardno, 2019). The context, content and consequence of the policy relating to the discharge of people living with dementia during the hospital discharge process is outlined (Bacchi, 2012) and analysed in the pre-pandemic context. The second section of the chapter considers how the policy issued from March 2020 during the pandemic impacted on the hospital discharge process for this demographic.

Chapter 4

How the methodology and appropriate paradigm for the research project was identified is outlined in chapter 4. How decisions regarding qualitative method were made is also discussed. Some of the challenges of recruitment and sampling are delineated. The role of patient and public involvement in the research is highlighted. The chapter discusses why the applied thematic analysis method (Guest, MacQueen and Namey, 2011) was chosen alongside the Appreciative Inquiry approach (Cooperrider and Fry, 2020). The decision to employ deductive analysis and utilise the theory of wellbeing identified by Kitwood and Bredin (1992) is justified. The importance of value, quality and reflexivity within the research process is discussed.

Chapters 5, 6, 7, 8 and 9

In chapters 5, 6, 7, 8 and 9 the findings of the applied thematic analysis (Guest, MacQueen and Namey, 2011) of the empirical interview study are presented. This includes the definition of wellbeing in this context and the expansion of the definition provided by Kitwood and Bredin (1992) of the three subthemes of Hope, Agency, and Personal Worth. The detail of these themes reveals the support needs of carers and patients, alongside the factors that support the maintenance of wellbeing. Agency is comprised of *processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*. Information regarding the participants and interviews is included. The findings of the analysis in relation to the Dream section of the Appreciative Inquiry (Cooperrider and Fry, 2020) cycle is also presented.

Chapter 10

In chapter 10 the findings from the systematic review synthesis are integrated with the findings from the empirical interview studies. Areas of agreement and divergence between the systematic review synthesis and the empirical analysis findings are identified. Further to this the impact that the pandemic may have in explaining the divergence is considered. There is discussion of how the findings have been used to begin the development of a framework aimed at ensuring the wellbeing of people living with dementia and their carers during the discharge process. Chapter 10 identifies the relationship between findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data analysis and the systematic review synthesis.

Chapter 11

In chapter 11 the key findings of the research project are discussed including how the findings align with the wider academic literature, how the social constructionist stance enabled a nuanced understanding of wellbeing, and the value of the Appreciative Inquiry process in identifying the changes required to promote wellbeing during the hospital discharge process. Lessons from the pandemic are pinpointed. The requirement for a change in focus towards the centralisation of wellbeing in the discharge process is discussed.

The impact of neoliberalist policies (Becker, Hartwich and Haslam, 2021; Mooney, 2012; Schrecker, 2016) on wellbeing during the discharge process are considered, together with the impact of COVID 19 and the implications of the findings for local NHS trusts, local councils, clinicians and relevant charitable organisations, such as Alzheimer's UK. Towards the end of the chapter, the strengths and limitations of the research project are considered and recommendations for future research made.

Chapter 12

Chapter 12 details the conclusions of the research project and implications of the findings.

A diagram of the thesis is included in figure 1.

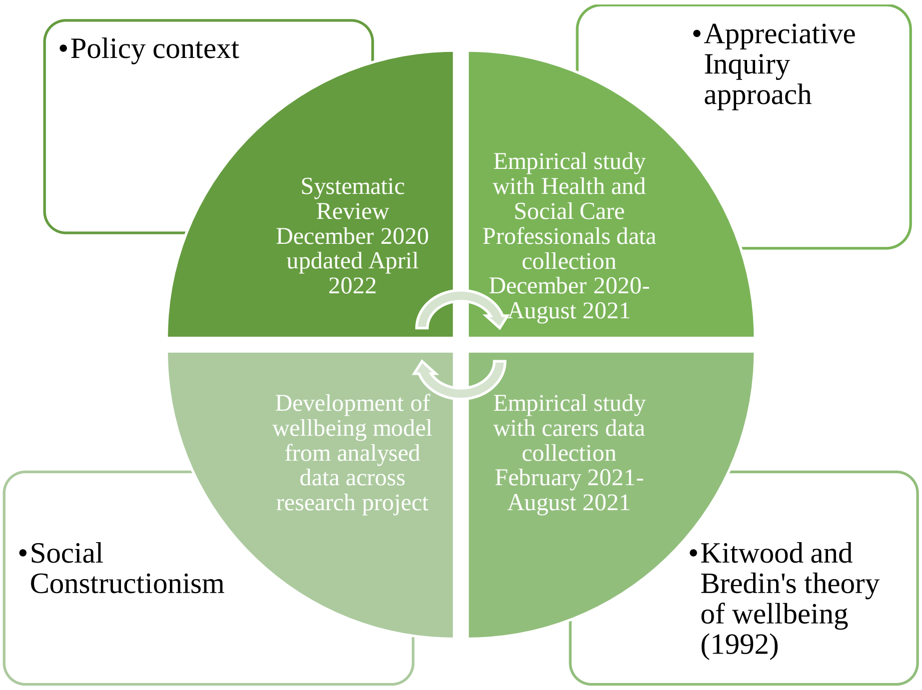


Figure 1. Diagram of thesis

The diagram represents the different components of the thesis visually including the time in which data was collected. The systematic review synthesis and findings from the empirical studies were instrumental in the development of the wellbeing framework. The Appreciative Inquiry approach (Cooperrider and Whitney, 2005) was used throughout the empirical research and the development of the wellbeing framework and is discussed extensively in Chapter 4. The theory of wellbeing developed by Kitwood and Bredin (1992) was used deductively during the analysis process and detail regarding this is presented in Chapter 4. The social constructionist ontology influenced all aspects of this thesis alongside the policy context which is outlined in Chapter 3.

Chapter 1. Introduction and literature review

1.1 Introductory preface

This thesis presents the findings of a qualitative exploration of the meaning of wellbeing for adults living with dementia and their carers during the hospital discharge process both immediately prior to and during the COVID 19 pandemic. The idea for this research project originated in November 2016, when myself and my supervisors, met to discuss aspects of hospital care for people living with dementia and the dearth of research evidence regarding best practice. Local nurse specialists identified the hospital discharge process as challenging for this patient-carer group and bereft of qualitative research focus. We could not have foreseen the 2020 COVID pandemic or the impact it would have on the research project.

Within this introduction, I will outline the research gap that became apparent as I carried out an informal scoping review of this topic during the research project's development in 2017, 2018 and early 2019. Identifying this gap allowed me to develop a research project which would be responsive and suitable to address the gap in the evidence base. The project had to be adapted to ensure compatibility with COVID 19 regulations in force during 2020 and 2021. Information pertaining to this is detailed within the methods chapter (4) of this thesis.

The concept of wellbeing for carers and people living with dementia during the hospital discharge process has not received the research focus required. The introduction will situate the thesis in the broader context of what is known about dementia, being a carer for someone with dementia, the experience of the hospital discharge process for a person living with dementia and their carer, and the importance of the topic of wellbeing. This will identify the gap in the evidence base that led to the development of research project outlined. The aims, objectives and research questions of the research project will be included at the end of the section and an overview of the structure of the thesis will be presented. I will begin with a reflective commentary regarding the origins of my interest in this subject and the background to this thesis.

1.2 Origins of this project

The origins of this project lie in my profession as a nurse and awareness of the complexities of the lives of people living with dementia and their carers. As a practicing nurse, I was employed in the hospital setting, caring for people living with dementia. I was aware of the difficulties often faced by carers and people living with dementia and particularly the complexities of hospital discharge. I was later employed on a project aiming to learn more about the experiences of people living with dementia in the hospital setting, with the end goal of creating a toolbox to support these individuals. Being involved with the project gave me a new perspective on what it was like to stay in hospital as a patient with cognitive impairment. I was able to view the hospital journey from both the patient, professional and carer perspective and thereby, witnessed the positive and negative elements of the hospital environment.

In my personal life, my grandfather is living with Alzheimer's disease and my mother in law's mother lived with Lewy body dementia. My best friend's mum also lived with dementia. Therefore, dementia is a presence in both my personal and professional life. I am aware of many of the difficulties around the hospital journey for people with dementia and their carers, and I have been the carer, on the end of the phone, trying to contact the correct hospital ward and locate my grandfather. On one occasion I made 22 phone calls to try and reach someone who was looking after my grandfather.

The experiences and perspectives of patients and carers have always been central to my professional practice. As a professional, I am also particularly interested in the opinions and knowledge of my colleagues in other disciplines. I believe strongly that patient, carer and professional opinion and input should be vital in shaping hospital and community health and social care services and policy, to meet the needs of all patient groups. All three groups should and must work together in partnership to enable safe and supportive care experiences and environments. Therefore, the importance of implementing a project focusing on the perspective of all stakeholders was evident to me.

When devising this project, I was informed by a supervisor that the dementia specialist team located at the local hospital had identified that there were problems with the hospital discharge process. I scanned the literature and discovered that there was limited qualitative evidence available about this topic which focused on the experiences of people living with dementia and their carers. I met with discharge co-ordinators and social workers who discussed their concerns about the discharge process. I knew the importance of creating an evidence base that could support the wellbeing of people living with dementia and decided to focus on this topic.

1.3 Context of the study

The hospital discharge process must be situated within the wider context of knowledge about dementia in both research and policy. Dementia is defined as a ‘syndrome associated with an ongoing decline of brain function’ (National Health Service, 2017), which includes: problems with memory; thinking; language; judgement and movement. The term can be used to include many individual categories of cognitive impairment, for example: mild cognitive impairment; Alzheimer’s disease or frontal temporal lobe dementia. The causes of dementia are not fully understood but appear multifactorial and complex. There is no current cure for dementia (Alzheimer's Society, 2019). How dementia has been understood, amongst academics and the general public, has undergone a radical shift in the last thirty years.

Originally pathologised as a neurological condition, it was identified by theorists such as Kitwood (1997), that the concept of dementia was also a socially constructed entity, characterised through social malignancy and depicted as a loss of personhood for the individual. The work of Kitwood (1997) challenged this dominant paradigm that categorized dementia as a medical condition leading to a loss of self through the deterioration of memory. Kitwood (1997) suggested that the practice of person-centered care and provision of holistic support for the individual living with dementia enabled the continuance of their personhood. This is in spite of the impact caused by the progression of the syndrome. Further to this, it was argued (Kitwood, 1997) that the negative attitudes displayed towards people living with dementia, by both society and the medical establishment, needed to change. It was contended (Kitwood, 1997), that positive ways of living with a dementia diagnosis needed to be prioritised. This fundamental shift in how dementia was viewed by the medical establishment and more broadly across society, led to revolutionary changes in both the care provided and the attitudes displayed towards people living with dementia. This positive advancement of the dementia paradigm coincided with significant increases in the numbers of individuals being diagnosed with dementia globally.

The World Health Organisation estimates the number of people living with dementia worldwide at 50 million. This figure is projected to increase to 75 million by 2030 and 152 million by 2050. It has been recognised that the vastly increasing numbers of individuals living with dementia, will lead to significant challenges for future health and social care structures internationally (Alzheimer's Disease International, 2017). In response to this, the World Health Organisation (2018) has issued guidance urging governments to develop comprehensive, multifactorial policy approaches, which address the enablement of sustainable and healthy living for this growing population group. In the UK, 1 in 3 people are expected to develop dementia in their lifetime and it is now the leading cause of death in the UK. The cost to the UK economy has been estimated at £ £34.7billion a year with predictions of a rise to £94.1 billion by 2040 incorporating costs to the NHS, social care costs and costs in unpaid care (Alzheimer's UK, 2019; London School of Economics and Political Science, 2019). It is apparent from the figures above, that the number of individuals living with dementia is already having a profound impact on the health of individuals and the economy of the UK. The importance of meeting the growing challenge of dementia prevalence has led to a significant policy response from the UK Government.

The Prime Minister’s Challenge on Dementia 2020 (Department of Health and Social Care, 2015), aimed to establish the UK as one of the best places to live globally with a dementia diagnosis. It aimed to encourage dementia friendly communities and support ongoing research into living well with dementia. Over 50 commitments were made within the policy paper and an evaluation of the success of those commitments is currently under review and has been anticipated since 2018. The publication (Deeks *et al.*, 2016) specifically addressed the requirement for support, in relation to wellbeing, to be available for both patients and carers in their day to day lives. This requirement was reinforced by a wealth of research, which has suggested that the impact of caring for an individual living with dementia can be profound and challenging (Feast *et al.*, 2016; Gao, Chapagain and Scullin, 2019; Sheehan *et al.*, 2021).

It has been established in academic literature that being a carer for someone living with dementia has a profound impact on all aspects of carer quality of life (Jones and Peters, 1992; Farina *et al*., 2017; Nuffield Trust, 2022). The Family Resources Survey (Department for Work and Pensions, 2022) identified that around 6% of the UK population are informal carers and around 1 in 8 people will be an informal carer in their lifetime (Carers UK, 2022). Whilst 60% of carers are female, carers over the age of 85 are predominantly male (House of Commons Library, 2022). Carer physical and mental health has been identified as significantly worse than the health of general population who do not care (Carers UK, 2021). During the pandemic in 2021, research was implemented via an online survey which included the responses of over 8,119 carers in the UK. The survey showed that carers were disproportionately affected with increased care responsibilities, and that significant loneliness was reported by 90% of the carers taking part in the survey (Carers UK, 2020; Carers UK, 2021). A report by Alzheimer's Research UK (2015) highlighted that the carers of individuals living with dementia, often experience social isolation and there can be a corresponding impact on their mental health. It is also established that there is increased financial, social, and physical burden on carers of people living with dementia, in comparison to other categories of carer (Brodaty and Donkin, 2009). It has been shown that there are categories of carer that face additional challenges, such as, carers for individuals with early onset diagnosis, and those from ethic minority backgrounds (National Institute for Health and Care Research, 2020). Therefore, it is important that government policy promptly addresses the needs of carers and people living with dementia.

1.4 UK carer policy

The UK government has issued guidance related to The Care Act (Department of Health, 2014a) which places a responsibility on local authorities to act in ways that support the wellbeing of carers. Local authorities must ensure the provision of a robust health and social care system, which values carer contributions and aims to support their wellbeing. This requirement ensures that there is the need for research to be available that can provide a vigorous evidence base to underpin policy initiatives.

There has been a significant amount of research focused on improving health and social care services and outcomes for people living with dementia and their carers (Fox *et al.*, 2017; Gibson and Yates, 2018; Richters *et al.*, 2018). Research has traditionally been segregated between being hospital or social care system focused and it has been acknowledged that there is scope for improvement within services in both sectors (Alzheimer's Research UK, 2015; Alzheimer's Disease International, 2017; Alzheimer's Research UK, 2018). Therefore, a research gap has opened in the transition from hospital to community-based care. The care provided in hospitals, for people living with dementia, has been heavily criticised in the UK (Alzheimer's Society, 2016). In response to this, guidance has been produced that aims to improve care standards, throughout the general acute hospital stay of people living with dementia (Dementia Action Alliance, 2018). Another identified problem related to the hospital discharge process is the education of nurses regarding care planning for people living with dementia and their carers.

1.5 Education of acute care nurses in dementia care.

There are skilled dementia specialist nurses present within acute care and their input has been shown to benefit people living with dementia and their carers (Griffiths *et al*, 2015). However, most acute nurses are not specialists in the care of people living with dementia and their carers. Collier, Knifton and Surr (2015) identified that there is a specific knowledge gap, within higher education institutions, in relation to the quality and quantity of undergraduate adult nurse education regarding people living with dementia and their carers. It has been identified that limited resources, and an absence of dementia knowledge within universities, has made incorporating robust dementia education into undergraduate programs challenging (Collier, Knifton and Surr, 2015). However, virtual training, educational programs incorporating the lived experience of people living with dementia and their carers, practice-based programs, and live model simulations were shown to have a positive impact on nursing attitudes, knowledge, self-confidence, and empathy (Alushi, Hammond and Wood, 2015; Maharaj, 2017; Kimzey, Mastel-Smith and Seale, 2019; Williams and Daley, 2021).

In 2007, Pulsford, Hope, and Thompson found that adult nurses were receiving an average of three hours of undergraduate teaching on the care of people living with dementia and their carers. Further to this, Traynor, Inoue and Crookes (2011) identified that there was no available framework to assess student nurse competency in the care of people living with dementia and their carers, leaving a gap in nurse education. A recent scoping review (Cariñanos-Ayala, Arrue and Zarandona, 2022) has shown that there is significant diversity among dementia education programs. The research found that the most common outcomes were knowledge, attitude and empathy but, due to the diversity of teaching methods, outcomes were not consistent. Furthermore, the only study which considered longitudinal outcomes identified that, after eight months, the education program had no long-term impact on attitudes, knowledge or empathy. Moreover, the review showed that adult nursing undergraduates are not being taught care planning in relation to people living with dementia or their carers, or about the structure of the services available for people with dementia in the system (Kim 2006). This is a significant gap in adult nurse education which will have a detrimental impact on the experience of people living with dementia and their carers at discharge.

1.6 Acute general hospital discharge process for adults living with dementia.

The general acute hospital discharge process has been identified as a particularly complex process for people living with dementia. A comprehensive factsheet released in November 2022 by Age UK (2022), outlines ways in which the discharge process can require complex decision making around discharge destination. This may incorporate capacity assessments, financial considerations, significant family input and the contribution of a multitude of clinicians, services, and assessment processes. Although these complexities may be involved in any discharge process, the nature of potential frailty, and fluctuating capacity in particular, can make the discharge process for people living with dementia significantly more complex (Stockwell-Smith *et al.*, 2018). Failings in the standards of care provided in hospital, and poor hospital discharge experiences, have been widely reported for older adults generally and for people living with dementia specifically (Healthwatch, 2015; Age UK, 2016; Macmillan, 2016). A report into the care provided during general and acute hospital discharge for people with dementia (Alzheimer's Society, 2016), identified a wealth of failings. These included high numbers of people living with dementia experiencing delayed discharges and significant numbers continuing to be discharged at night. The negative impact that poor hospital discharge experience has on patient outcomes has been illustrated in previous research findings (Ray, Ingram and Cohen-Mansfield, 2015) and highlights the importance that research is undertaken, which addresses how the hospital discharge process can be improved.

It is important to note that adults living with dementia may be admitted to inpatient psychiatric care for assessment, care planning purposes or changes to treatment plans (Wolverson *et al*, 2022). Discharge from these facilities is comprehensive, specialist and guided by mental health professionals trained in the care of adults with psychiatric conditions (Gondhalekar *et al*, 2021). However, the discharge process from acute general hospitals, for people living with dementia, will rarely receive the benefit of the specialist skills and knowledge of psychiatric professionals.

The Health Foundation (2023) defines ‘acute care’ as when ‘a patient receives active, short-term treatment for a condition.’ It further defines this as including ‘treatment for a severe injury, period of illness, urgent medical condition, or to recover from surgery.’ This context is representative of the hospital discharge process as defined in this thesis and is not to be confused with the specialised psychiatric discharge process.

There are several specific conditions that may cause a person living with dementia to be admitted to hospital. Studies have identified that being admitted to an acute hospital for a person living with dementia is rarely connected with their dementia diagnosis (Natalwala *et al*, 2008; Chang *et al*, 2015). Longitudinal quantitative research has identified that the most common reasons for a person to be admitted to an acute general hospital are: ‘acute delirium; newly onset stroke; pneumonia; fall-related hip fracture; and urinary tract infection’ (Natalwala *et al*, 2008, p. 503). Chang *et al* (2015) identifies that the reasons behind hospital admission for this demographic group, reveal that many community-based individuals living with dementia are vulnerable to dehydration, falls and bronchial issues.

Long *et al* (2013) identified that due to the reasons that people living with dementia are admitted to hospital, they are vulnerable to a number of adverse effects. Pressure ulcers, falls, dehydration, delirium, and hospital acquired infections are all likely to be experienced by people living with dementia who are admitted to hospital (Long *et al*, 2013; Fog, Griffiths, Meredith and Bridges, 2018). One of the reasons for experiencing these adverse effects are that people living with dementia are likely to be experiencing poor mobility and cognition following a fall, or when experiencing a health diminishing condition, such as pneumonia (Kosse *et al*, 2015).

Another significant issue that arises during inpatient stays for people living with dementia is the under treatment of pain. Tsai, Brown and Inder (2022) identified that there is an underusage of pain assessment tools for people living with dementia in hospital. Long *et al* (2013) identified that these adverse events are largely caused by both direct and indirect causes of harm. Direct causes include ineffective assessment and treatment, indirect causes include discrimination and limited availability of trained staff (Long *et al*, 2013).

In the following section I will outline the stages of the discharge process and consider why there might be some failings within the discharge process. Figure 2 depicts this process visually.

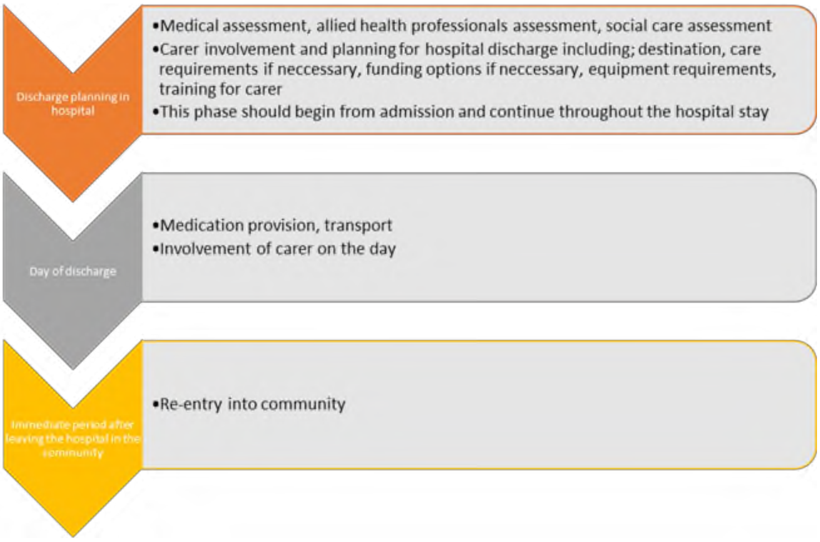


Figure 2. Outline of the discharge process.

The reasons behind the failings identified in the hospital discharge process are multifaceted (National Audit Office, 2016; Kings Fund, 2017). They cannot be simply distilled to issues with funding, staffing, or training, although weaknesses in all of these areas, have been identified as contributing to failings in the hospital discharge process for older adults and adults living with dementia. Previous research has identified that discharge must be viewed as a process which extends beyond the patient leaving the hospital and incorporates their experience in the community in the immediate post-hospital discharge period (Mockford *et al*., 2017). Therefore, there are two distinct phases to the discharge process: the hospital-based segment and the corresponding community phase. I will consider both segments of the discharge process separately, as this is the approach most often taken by research literature and policy documents. However, the issues and complexities of both the hospital and community phase of the discharge process, are fundamentally related to one another and cannot stand in isolation (Care Quality Commission, 2018).

The requirement to ensure a positive hospital discharge experience for people living with dementia and their carers, has long been acknowledged in both research literature, and government policy (Cox, 1996; Department of Health and Social Care, 2013). There are several identified reasons why people living with dementia and their carers are experiencing negative hospital discharge experiences. Many researchers have identified that the problem may be partly attributable to the medicalised setting itself. There is a well-established literature highlighting the dominant medical model that permeates health care (Illich, 1974; Stacey, 1988; Nettleton, 2006) and is associated with reductionist and paternalistic care provision, which nullifies the potential social causes of ill health. The impact of the dominance of this reductionist and paternalistic model on health provision, continues to be analysed in academic discourse in the modern technological era (Morley and Floridi, 2020; Varley and Varma, 2021). The ongoing role of iatrogenesis as applicable within dementia care has been a recent demonstration of the ongoing relevance of these theories (Morris, McCloskey and Bulman, 2022).

Other research has suggested that it is not only the dominance of the medical model, and the paternalistic approach of the NHS, which can lead to negative outcomes and experiences of the hospital discharge process, but also the organisational structure of the hospital. Barry and Yuill (2011) argue that the organisation of the hospital itself is designed to undermine patients and prevent their individual requirements from being asserted. This corresponds with Goffman's (1961) seminal argument that the needs of the institution, whether medical, educational or bureaucratic, are always placed above the needs of the individual, and that a by-product of this is the suppression of subjective needs. Goffman (1961) elaborated further that the 'total institution', such as the hospital context, often requires the individual to comply with its own procedures and rules and cannot accommodate individual requirements. Recent theorists have built upon this work and identified the ways in which the modern hospital continues to correspond to the concept of the total institution (Jenkins, Burton and Holmes, 2022). The way in which the electronic patient record, and drug administration computerized systems, operate as mechanisms of control in the twenty first century underscores the continuing relevance of these theoretical viewpoints (Jenkins, Burton and Holmes, 2022).

The work of Foucault (1975) builds on this argument, to infer that institutions tend to become focused not on the merit or value of individual actions and outcomes, but simply on whether individuals are following the rules of the institution. A brief overview of the literature relating to the hospital discharge experiences of carers and people living with dementia, reveals that these themes emerge time and again in reports (Care Quality Commission, 2018) and research findings (Mockford, 2015). The medical model and needs of the hospital organisation appear to trump patient requirements consistently, even though policy and research findings clearly require a different, individualised approach to patient care and discharge processes (National Institute for Health and Care Excellence, 2015; Dementia Action Alliance, 2018).

It has also been noted that the neoliberal agenda within the healthcare system, whereby responsibility and risk have shifted away from the state and towards the individual by cutting public funded services, care and organisations, has impacted on the discharge process (Harvey, 2007; Mooney, 2012; Venugopal, 2015) This has led to reduced services and an emphasis on the individual making choices, rather than receiving support either financially or through care (Schrecker, 2016). This reduction in capacity has led to individuals and families having to, 'fend for themselves', during the discharge process with limited input from either the community, or hospital services, into organising the transport, place of discharge, equipment required etc., as these are deemed to be largely the responsibility of individual and their families (Venugopal, 2015). Therefore, the responsibility for the discharge process has been shifted to the individual being discharged, and when this individual is living with dementia, it leads to a complicated and stressful process for the carer and individual, with little support available.

Factors that contribute to negative and positive experiences of hospital discharge, for people living with dementia and their carers, will be explored further within the systematic review section of this thesis. A summary of some of the key issues identified frequently in the literature include: the exclusion of carers and people living with dementia from the discharge decision making process (Bauer, Fitzgerald and Koch, 2011; Mockford *et al.*, 2017); poor community service provision and social care involvement within the discharge process (Kable *et al.*, 2015; Jamieson *et al.*, 2016); an absence of support for carers of adults living with dementia (Shyu, 2000; Coleman and Roman, 2015; Kuluski and McGeown, 2017); the privileging of hospital needs above patient wellbeing and patient centered care (Norman, 2003; Huby et al., 2004; Digby, Lee and Williams, 2018b) and insufficient discharge planning procedures and policies during this period (Sewter, 2014; Gilmore-Bykovskyi, 2017).

In the UK, guidance around the importance of robust discharge planning and the importance of including carers and patients in the process, has been explicitly available since 2015 (National Institute for Health and Care Excellence). This guidance (National Institute for Health and Care Excellence, 2015) applies officially to England only. The devolved governments of Wales, Northern Ireland and Scotland are responsible for approving the applicability of National Institute for Health and Care Excellence (NICE) guidance on an individual basis. However, it is standard practice to adopt the guidance, after review, within the devolved nations of Wales and Northern Ireland (National Insititute for Health and Care Excellence, 2013). Although not officially bound to follow the guidance, clinicians and commissioners in Scotland are guided to consider NICE guidance when making decisions, and in their practice (Kohli and Tannahill, 2009). Scotland has an official body known as SIGN (Scottish Intercollegiate Guidelines Network). However, their only available guidance in relation to the discharge process is a discharge document from 2012. This guidance is not specific to people living with dementia and is limited (Scottish Intercollegiate Guidelines Network, 2012).

Since publication of the guidance, no new UK research has emerged to assess whether there has been an impact on discharge practices within the UK. However, information from the National Audit Office (2016) has suggested that improvements in the discharge planning process have not occurred since implementation. Findings from the National audit of dementia (Royal College of Psychiatrists, 2017, p. 67) identified that 1 in 4 carers are not being given any notice of impending hospital discharge. This suggests that the involvement of carers during the discharge decision making process is still problematic. These findings are further supported by the Care Quality Commission (2018), who have also critiqued the hospital discharge process, and identified several improvements which should occur, including greater integration between health and social care structures (Care Quality Commission, 2018).

The need for further integration between social and healthcare services, has been discussed at length (Age UK, 2016; Kings Fund, 2017). A lack of capacity and resource; an absence of joined up working due to the separation of governance; poor leadership, the prioritisation of targets and commissioning objectives; fears around information sharing and a social care funding crisis; have all been implicated in failings within social care provision during the hospital discharge process. Delayed discharges and a failure to complete the necessary assessments prior to discharge have been highlighted as particular issues (Age UK, 2016). The Nuffield Trust (2021) identified that between 2010 and 2020 there was a 96% increase in delayed hospital discharges. The number one reason for delayed hospital discharge was the shortage of available care packages in the community. Following this, delays in acute treatment within the hospital and a shortage of care home placements were identified as being responsible for delayed discharge processes (Nuffield Trust, 2021). Interestingly, data on the causes of delayed discharges has ceased to be collected centrally since 2020 (Limb, 2022). The reason this data is no longer collected is unclear.

Although the NHS Long Term Plan (NHS England, 2019), aims to overcome the absence of joined up working by placing social workers on hospital wards, the continued privileging of funding for healthcare services suggests that the medical model is still prioritised above social understandings of health and wellbeing. This should be reassessed in the current context of an aging population. This is particularly important in the light of evidence suggesting that pressures on social care funding directly impact on mortality rates for this age group (Watkins *et al.*, 2017). The historical divide between health and social care funding and practice, has been increasingly criticised. There have been calls for a new funding and commissioning model (Care Quality Commission, 2018, p. 6), which acknowledges the vital role that social care services play in the hospital discharge process and challenges the notion that the two services can be separated. The UK Government's ongoing failure to deliver the green paper on social care, whilst simultaneously delivering The NHS Long Term Plan (NHS England, 2019), highlights the challenge of social care provision and the continued prioritisation of healthcare policy.

The Health and Care Act (2022) established Integrated Care Boards and integrated Care Partnerships (ICP) as legal entities in July 2022. The Integrated Care Systems, as outlined in the white paper (NHS England, 2022a), aim to integrate health and social care in relation to commissioning and practice. This change in policy approach has been largely welcomed but it is too early, following the implementation of this policy, to identify any outcomes in relation to the hospital discharge process. However, in June 2022 the then Secretary of State for Health and Social Care, and the Secretary of State for Levelling Up, Housing and Communities, issued an invitation for expressions of interest to become a Discharge Integration Frontrunner site to Integrated Care Systems (ICS). The objective of the Discharge Integration Frontrunner Sites is stated to be developing and testing radical new approaches to post-acute care, that see patients discharged to, 'the right place, and with the right support, in a safe and timely manner' (Department of Health and Social Care, 2022a, p.1). One of the aims of the discharge integrator front runner program is for ICS's to 'design and test new service models, such as the delivery of a more integrated model for intermediate care across existing health and social care portfolios' (Department of Health and Social Care, 2022a, p.1). The substance of these new models is not evident. Whether these models will be able to address the issues of delayed discharge and the problems outlined within this chapter is also unknown.

Although the Care Act (Department of Health, 2014) calls for local authorities to promote the wellbeing of carers and care receivers, in reality the reduction in social care funding (Age UK, 2016) contributes to social care failings and increasingly poor discharge experiences. Research findings (Mockford *et al.*, 2017) have shown that appropriate, robust, community based social care services are often not available at the point of discharge for people living with dementia. This finding is evident, even though there is a statutory duty on local authorities to provide these services under The Care Act (Department of Health, 2014). There is a significant gap between policy, theory, and current practice, for both health and social care aspects of the hospital discharge process. While it is evident that, within the context of social care, some of this gap is due to funding issues, the research findings briefly mentioned above suggest that there is a more complex overall picture of why the hospital discharge process is so often a negative experience for this demographic, which goes beyond just care staff availability and funding concerns (Bauer *et al.*, 2009). The announcement, in November 2022, by the Secretary of State for Health and Social Care that £500 million will be made available to support both social care provision, and bed capacity in hospitals, was not regarded by groups such as Age UK, or The Kings Fund, as sufficient to address the systemic problems within the discharge process (Department of Health and Social Care, 2022b; Croner-i, 2022). The funding was criticised as being merely a stop gap, unable to address the problems inherent to the hospital discharge process.

1.7 The research gap

There is limited research available that addresses the discharge process specifically for people living with dementia and their carers. It is important that qualitative research is available for this topic and this carer dyad to enable a deeper understanding of the complexity of the hospital discharge process experience, and the challenges faced by this population (Johnson and Waterfield, 2004). It is important to access lived experience to understand the intricacies of the process beyond what quantitative data can indicate. There has been little qualitative research into why the gap between policy, research findings and practice exists for this patient and carer group.

It is important that qualitative research is available for this topic and this carer dyad to enable a deeper understanding of the complexity of the hospital discharge process experience and the challenges faced by this population. It has been identified in numerous studies that more research around the process is required (Shippen, Young and Woods, 2011). Available research findings often focus exclusively on either hospital based or social care aspects of hospital discharge (Cox and Verdieck, 1994). This approach has historically made sense as these two sectors have been funded separately and operated separately. However, it is my contention that this is a flawed perspective of a process that is fundamentally co-dependent. This is even more applicable following the introduction of ICS's and new ways of collaborative working between the sectors.

The study will avoid this shortcoming by considering both the hospital and social care elements of the discharge process simultaneously. Further to this, available research is often focused on the involvement of patients and carers and not on factors that ensure a positive experience and outcome of the discharge process (Shippen, Young and Woods, 2011). This is a significant issue as it has been identified that some patients do not want to be explicitly included in decisions made during hospital discharge (Huby *et al.*, 2004). Therefore, a greater research emphasis on identifying the holistic factors crucial to a positive discharge experience, and potential improvements to current discharge processes, needs to be adopted to address the gaps in the current evidence base.

Although policy is available that addresses transitions from hospital to home or residential care (National Institute for Health and Care Excellence, 2015) for adults with social care needs, the requirements of individuals living with dementia are not specifically addressed. This is problematic as people living with dementia, and their carers, may have different needs to other patient groups, particularly in relation to capacity assessments. An apparent juxtaposition between health and social care policy and practice is the importance of patient and carer wellbeing. Although the promotion of wellbeing is strongly established in policy and law (National Institute for Health and Care Excellence, 2015; Department of Health, 2014a; NHS England, 2019) it has not yet received much research activity and does not appear to be explicitly addressed in health and social care practice.

1.7.1 Why wellbeing for people living with dementia and their carers deserves further attention.

The importance of patient and carer wellbeing has not featured prominently in research focusing on hospital discharge for people living with dementia. Carer and patient wellbeing often appear to be overlooked in favor of hospital concerns, such as the pressure to facilitate timely discharge (Stockwell-Smith *et al.*, 2018) and mitigation of risk (Emmett *et al.*, 2014). No research has been conducted which considers how patients, carers and health professionals understand the concept of wellbeing or whether it is currently utilised in hospital discharge practice. Research findings have argued that wellbeing is a holistic concept which can be contradictory (Dodge *et al.*, 2012; La Placa, McNaught and Knight, 2013) and includes aspects of the physical, psychological, social and spiritual. In correspondence with this, the UK Government has defined wellbeing as including ‘physical, social and emotional dimensions’ (Department of Health, 2010, p. 13) of health. This is in harmony with the World Health Organisation definition (2019) and it has established its commitment to the embedding of wellbeing within future policy initiatives and publications (Department of Health, 2014c). Further to this, the UK Government has identified that wellbeing and health are intrinsically linked and highlighted that there are huge gaps in the evidence base concerning wellbeing (Department of Health, 2014b). One particular gap identified is the paucity of evidence around what increases wellbeing in different contexts and during different processes. This is a significant oversight, as wellbeing has been identified as a better health indicator than the quality-of-life index. This quantitative measurement of wellbeing, which features standard indicators, has been ubiquitous in modern health and social care research. It has been critcised as overly prescriptive (Ferrans and Powers, 1985) and lacking in flexibility. Further research into understanding the term wellbeing may be able to address this criticism. It has been argued that ideas of patient and carer wellbeing should be central to all health and social care decision making (Department of Health, 2014c). Recently, the requirement for further research exploring and evaluating the concept of wellbeing, in different settings, has been recognised by UK research councils (Economic and Social Resarch Council, 2019).

Although national policy and guidelines request the support of patient and carer wellbeing during the hospital discharge process (NICE, 2015), there is no guidance available addressing how to achieve this in practice. In the early scoping exercise, no research was identified which explicitly considered how ideas concerning wellbeing impact upon hospital discharge practice. Nor was there any exploration of how people living with dementia, their carers, or health and social care professionals. understand wellbeing in this context. Therefore, a requirement for research which addressed this gap, and identified the tenets of the concept of wellbeing, and what supports its maintenance was evident. In the next section, I will address the aims and objectives of this research project. I will include the caveat that this research project went through many iterations and had multiple protocols across two qualitative studies requiring NHS Research Ethics committee approval, and HRA approval, a systematic review, a university protocol, and a post COVID 19 protocol.

1.8 Research aim and objectives

Given the identified evidence gap, the aim of this research project was to explore the facets of wellbeing for people living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. The research project was planned in 2019 before the pandemic and adapted to the restrictions required by COVID 19. Further detail of the changes in method and focus that the project underwent, and the opportunities and restrictions imposed by the pandemic, are outlined in the methods chapter. A secondary aim included contributing to the developing evidence base available to policy makers, and clinical professionals, in relation to the wellbeing needs of this dyad during the hospital discharge process in the post COVID 19 climate. This included the aim to define the term wellbeing in this context.

The objectives include:

1. Conducting a qualitative systematic review to identify and synthesise available evidence, regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. *What are the experiences of people living with*

dementia and their familial carers, during the hospital discharge planning process?

2. Identifying factors (environmental, organizational, resource or social) that impact the physical, emotional, and social wellbeing of people living with dementia and their carers, during the hospital discharge process, through interviews with health and social care professionals and carers.

3. Exploring if, and how, the wellbeing and support needs of people living with dementia and their carers are addressed in current hospital discharge practice, or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

4. Identifying how guidance from ‘COVID 19 hospital discharge requirements’ (Department of Health and Social Care, 2020a) impacted on the discharge process during the COVID 19 pandemic.

5. Developing a framework based on the perspectives of carers and healthcare professionals to ensure wellbeing, in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Ultimately the research questions I adopted evolved during the span of the research project and the impact of the COVID 19 pandemic and became: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

1.9 Summary of chapter and outline of structure of the thesis

This chapter has outlined the wider academic and political context in which this research project was designed and implemented. The importance of research that addresses the requirements of people living with dementia and their carers, has never been greater due to the rising number of people living with this condition. The perceived failings of the hospital discharge process, and the emerging importance of the term wellbeing in policy documentation, has revealed the research gap, justifying the research aim and objectives of this research project. Moreover, the recent changes to the health and social care context in relation to the establishment of ICS’s and ICP’s, and the impact this may have on the hospital discharge process for this carer dyad, denotes the importance of this research project in aiding to develop the evidence base in this area.

The next section of this thesis details the method of the systematic review, and the synthesis of the available qualitative research regarding the evidence relating to the experience of people living with dementia, and their carers, of the hospital discharge process. The limitations and conclusions of the systematic review are discussed, enabling a comprehensive overview of prior research in this topic area. Subsequently, the methods section of this thesis details how the research project was implemented and how the author made choices about methodology and method. Following this, the data itself is presented, including information regarding the participants of the study. The final section of this thesis examines what the data reveals about wellbeing during the hospital discharge process for this carer dyad, how the data develops the findings of the systematic review, the implications for policy makers, National Health Service Trusts, and clinicians, and a potential framework for supporting wellbeing during the discharge process in the post COVID 19 context.

Chapter 2. Systematic review

2.1 Introduction to chapter

This chapter presents a systematic review of the available qualitative evidence concerning the hospital discharge process. In the previous chapter, it was identified that there have been a number of concerns raised regarding the standard of hospital-based care for people living with dementia (Alzheimer's Society, 2016), including concerns with regard to the discharge process (Healthwatch, 2015). Despite the identification of hospital discharge as problematic for people living with dementia, limited research has focused on the hospital experience or hospital discharge for this patient group. Therefore, the experience of people living with dementia during this process has not been comprehensively investigated.

The lack of evidence relating to patient experience of discharge, combined with evidence of a negative impact on wellbeing following hospital admission, suggests that clinicians, stakeholders, and commissioners, do not have access to a patient informed evidence base that can enable them to support wellbeing during hospital discharge. Therefore, it is vital that evidence indicating the factors that can safeguard wellbeing is synthesised to provide commissioners and clinicians with the information required to support patients during hospital discharge.

A qualitative systematic review of the experiences of people living with dementia and their carers during the hospital discharge process, has not been previously undertaken to the knowledge of the researcher. Therefore, this review was undertaken to clarify the key literature related to the research topic; identify how the thesis expands upon what is already known about the topic, prevent duplication of research; and allow for a more nuanced approach to any planned empirical work (Clark, 2016).

The systematic review aimed to address the following questions:

2.2 Primary aim

What are the experiences of people living with dementia, and their carers during the hospital discharge planning process?

2.2.1 Secondary aims

Identify the key factors that should guide health care professionals in safeguarding the wellbeing of patients living with dementia, during the discharge planning process from hospital?

Identify any omissions in the evidence base, regarding the experience of people living with dementia, and their carers during the hospital discharge process.

The primary aim and secondary aims chosen enabled the broad identification of the experience of hospital discharge, alongside the factors that ensure wellbeing for people living with dementia during the discharge process. The identification of any omissions, within the evidence available, regarding the experience of the discharge process was also chosen to highlight any gaps evident. The methods employed in the systematic review process, including the search strategy, shall now be outlined. The protocol for the systematic review was published via Prospero.

2.3 Methods of systematic review

2.3.1 Protocol

The protocol for the systematic review was registered with Prospero (registration number: CRD42019131815) Further details can be found on the Prospero website. The original plan for the systematic review and the systematic review protocol are included in the appendices.

2.3.2 Search strategy

Search terms included both primary qualitative and mixed methods studies. Both published and unpublished or grey literature was included from 1990 to December 2018 in the first instance. I identified that care for people with cognitive impairment, including dementia, before 1990 would not be compatible with modern person-centred care approaches (Kitwood, 1997). The systematic review searches were re-run to be inclusive of all publications until 1 April

2022 in the second instance. The search terms and number of identified articles for each database were recorded. The following sources were searched to identify published literature using Boolean operators including truncation: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present; Embase (Ovid); CINAHL (EBSCO); PsycINFO; Scopus; SCIE: Social Care Online; Pubmed; Proquest; Cochrane; Web of Science. The search terms outlined in table 1 were utilised to search the above sources. The terms were adjusted to meet the requirements of the specific data base. The reference lists of all included studies were hand searched to identify further relevant studies.

Table 1. Search terms utilised in the database search process.

Table 1						
Sample (patient)	**Sample (carer)**	**Sample (Dementia)**	**(Phenomena of Interest) Discharge from hospital**	**Design**	**Design Evaluation Experience**	**Research Type**
Adult	Family	Dementia	Return home process	Interviews	Perception	Qualitative
In-patient	Relative	Cognitive Impairment	Leaving hospital	Focus groups	Perspective	
Patient	Carer	Confusion	Discharge planning	Observation	View	Mixed methods
	Family Carer	Alzheimer’s			Experience	
	Family carer	Frontal temporal lobe dementia			Insight	
	Informal carer				Opinion	
	Carer					
	Spouse/wife/ husband					
	Child/daughter/ son/grandchild					

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type framework) (Cooke, 2012) outlined in table 2 was utilised in the development of the search strategy. The SPIDER framework has been recognised as more appropriate to systematic review search strategy design for qualitative reviews than the quantitatively focused PICO (Population, Intervention, Comparison and Outcomes) (Methley *et al.*, 2014). It enables the search to focus on the characteristics important to qualitative research, enabling the search to access the correct research designs, samples, and topics.

2.3.3 Inclusion and exclusion criteria

Table 2. SPIDER framework and inclusion criteria for review

Table 2	
Sample	Patients and carers of adults with cognitive impairment
Phenomena of Interest	Discharge from hospital process for patients and carers/relatives
Design	Interviews, focus groups, case studies, ethnographies, observational studies,
Evaluation	Experiences
Research Type	Qualitative, mixed methods

Table 3. Inclusion and exclusion criteria beyond SPIDER framework

Table 3		
	Inclusion Criteria	Exclusion Criteria
Publication	Peer reviewed journals, reports, audits, conference proceedings, unpublished thesis	Opinion pieces, editorials
Language	English language	Any other language

2.3.4 Data screening process

The titles and/or abstracts of studies retrieved using the search strategy and those from additional sources, were screened by myself in entirety (n= 6342). The second reviewer (CA) screened 20% of the results to ensure that no studies were being incorrectly excluded or included at that time (n= 1268). Studies that did not meet the inclusion criteria outlined in table 2 and table 3 were excluded (n= 6123). Decisions about inclusion and exclusion of studies, were decided in a series of meetings between the two reviewers where disagreements regarding inclusion were discussed to achieve consensus. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram outlines the decisions made. The full texts of eligible studies were retrieved and assessed in full by the primary reviewer to ensure they met the inclusion criteria as outlined in the PROSPERO protocol (n= 219).

After the re-run of the searches in 2022, (n=2,579) articles were returned and entered into an endnote file for review. The titles and/or abstracts of studies retrieved using the search strategy, and those from additional sources, were screened during this update. The full text of 35 eligible studies was retrieved and assessed in full.

2.3.5 Data extraction

The data was extracted using a customised electronic data extraction form, tailored to the qualitative systematic review methodology, from the National Centre for Biotechnology Information (2011). The data extracted included: review authors; title and year; aim; study design; participant information (includes staff, carer or patient); inclusion and exclusion criteria; setting; design; summary of content and findings including themes; quotes; strengths and limitations; recommendations and reviewer comments. An example is included in the appendix (Chapter 14, Item 11).

2.3.6 Quality assessment

Risk of bias and the methodological quality of each study was assessed using the Critical Appraisal Skills Programme tool (2018) (CASP) specific to the design of the research assessed.

2.3.7 Meta ethnography synthesis process

In determining how to synthesise the studies, it was decided to use the method of meta ethnography (Noblit, Hare and Hare, 1988) due to the ability of this method to move beyond the findings of an original study to identify overarching theories, patterns and processes. Meta-ethnography has been characterised as different from other qualitative synthesis approaches. The systematic reviewer uses a translation synthesis to explore the theorised findings, such as themes or concepts, from the initial study alongside the raw data to transcend the findings of the individual studies, and create a new synthesis (Noblit, Hare and Hare, 1988). Other author's interpretations of the meta ethnography process were used to guide the synthesis (Britten *et al.*, 2002; Campbell *et al.*, 2012). The worked examples in the papers by Campbell *et al.* (2012) and Britten *et al.* (2002), helped illuminate the method relevant for developing the 'line of argument' synthesis central to meta-ethnography, and which was implemented in my own review. The seven steps outlined were used as a guide to the process: getting started; deciding what is relevant to the initial interest; reading the studies; determining how the studies are related; translating the studies into one another; synthesising translations and expressing the synthesis (Noblit, Hare and Hare, 1988; Britten *et al.*, 2002; Campbell et al., 2012).

1. Getting started: revisiting the original protocol for the study and ensuring that the papers selected for final inclusion addressed the research question.
2. Deciding what is relevant to the initial interest: papers were assessed to ensure that they could contribute appropriate data to the subject of the systematic review.
3. Reading the studies: studies were read at least twice by myself to develop familiarity with the methods and findings of the papers. Data was extracted into an excel table, in accordance with the systematic review process.
4. Determining how the studies are related: relationships between the papers were identified with common occurring themes selected.

During the data extraction process, the key themes and findings of the paper were entered into a spreadsheet. These themes and findings were then examined further and entered into a separate spreadsheet, so that relationships between the studies could be visually identified. All identified themes and findings were re-read and the key overarching themes that were common across the studies were extracted. This was a challenging process due to the high number of studies included, and the wide range of experiences for carers and patients. An example of how this was achieved is included in table 4 below.

Table 4. Determining how studies are related.

Table 4
Theme: Carers excluded from the discharge process
Bauer, Fitzgerald and Koch (2011) Carers not invited to discharge meetings
Telford (2015) Carers felt unheard with health and social care staff making decisions without their involvement
Coleman and Roman (2015) Carers not recognised as members of the health and social care team

Most papers key findings translated into one another readily. For example, the exclusion of the patient from the discharge process, the need for availability in relation to community services, and the requirement for more robust discharge policies and procedures. The included papers health and social care, geographical, funding and system settings were diverse. However, there were broad commonalities in patient experience, and in the recommendations for the improvement of the discharge process based on individual study findings. An example of this is shown in the appendices (Chapter 14, Item 12)

5. Translating studies.
6. Synthesising translations
7. Expressing the synthesis

It is difficult to explain the process of synthesis as the qualitative process cannot be broken down into a set of generic steps. This has been identified previously (Britten *et al*., 2002). The themes identified were grouped into separate areas and overarching themes identified. The author checked that each theme fitted into each overarching theme and re-read the original studies to ensure that the themes reflected the findings of the all the included papers.

2.4 Results

2.4.1 PRISMA flow diagram

Figure 3 represents the PRISMA flow diagram and shows the process of identifying relevant research articles for inclusion in the systematic review. A table detailing a sample of the extracted data from the original included studies is located in the appendices (Chapter 14, item 11).

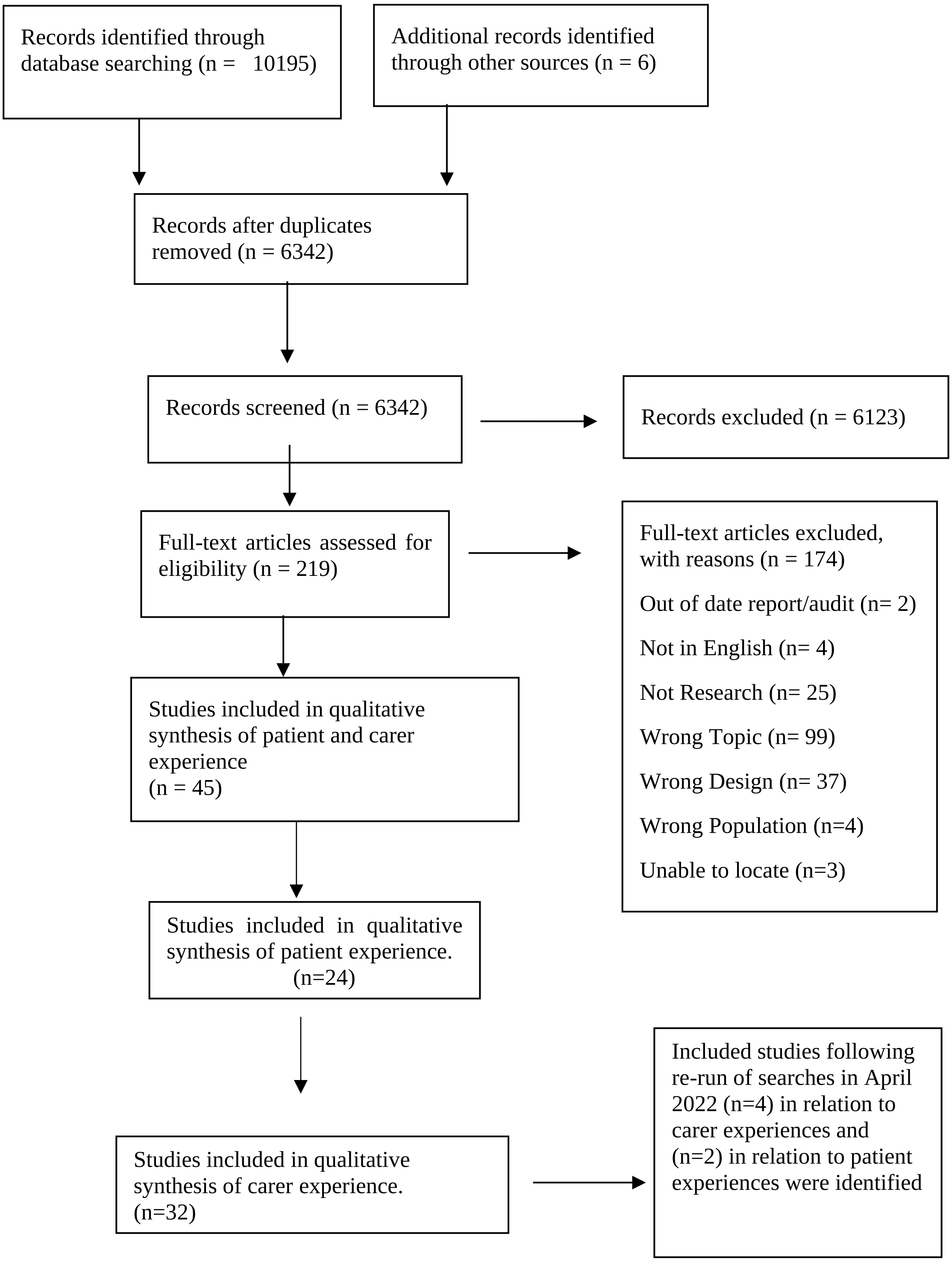


Figure 3. Prisma flow diagram of included and excluded studies

2.4.2 Patient experience synthesis

24 articles (Boaden, 2016; Bauer *et al.*, 2011; Bauer, Fitzgerald and Koch, 2011; Cumbler, Carter and Kutner, 2008; Coleman and Roman, 2015; Deeks *et al.*, 2016; Dyrstad, Laugaland and Storm, 2015; Digby, Lee and Williams, 2018b; Emmett *et al.*, 2014; Gilmore-Bykovskyi, 2017; Huby *et al.*, 2004; Jamieson *et al.*, 2016; Kable *et al.*, 2015; Kadushin and Kulys, 1994; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Kuluski and McGeown, 2017; Macmillan, 2016; Norman, 2003; Parliamentary Health Service Ombudsman, 2016; Poole *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Rhynas *et al.*, 2018; Telford, 2015) were included in the synthesis of patient data with 10 articles originating from the UK, Seven from Australia, five from the USA, one from Canada, and one from Norway.

17 of the studies included are primary research studies involving qualitative methods. Five are case studies (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016).

Following the re-run of the searches in 2022, one case study and one primary study (Department of Health and Social Care, 2015; Schreiber, Powell and O'Dowd, 2018) in relation to the experience of patients was included. A further two systematic reviews (Pritchard *et al.*, 2020; Richardson *et al.*, 2019) were identified and are discussed in the introduction.

2.4.3 Carer synthesis

32 articles were included in the synthesis in relation to carer experiences (Bauer, Fitzgerald and Koch, 2011; Bauer et al., 2011; Bloomer *et al*, 2016; Coleman and Roman, 2015; Cooper and Deeks, 2012; Cox, 1996; Deeks *et al.*, 2016; Dyrstad, Laugaland and Storm, 2015; Emmett *et al.*, 2013; Emmett *et al.*, 2014; Fitzgerald *et al.*, 2011; Gilmore-Bykovskyi, 2017; Gupta *et al.*, 2006; Jamieson *et al.*, 2016; Kable *et al.*, 2015; Kadushin and Kulys, 1994; Kuluski and McGeown, 2017; Levine, 2002; Macmillan, 2016; Mockford *et al.*, 2017; Poole et al., 2014; Rhynas *et al.*, 2018; Sewter, 2014; Shippen,

Young and Woods, 2011; Shyu, 2000; Telford, 2015). Two were case studies (Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017) and two reports (Boaden, 2016; Parliamentary Health Service Ombudsman, 2016). 26 articles were primary research studies. Nine articles originated from the UK, seven articles originated from Australia, four from the USA, one from Norway, one from Taiwan and one from Canada.

Following the re-run of the searches in 2022, four (Dabelko-Schoeny *et al.*, 2020; Sanatinia *et al.*, 2020; Sawan *et al*., 2021 Fry *et al.*, 2022) primary research articles regarding the experience of carers were identified as appropriate for inclusion and have been summarised and incorporated into the findings.

2.4.4 Discussion of study quality

All included studies were subjected to the CASP process allowing the author to assess their methodological quality. The purpose of a qualitative review is to support available evidence by amalgamating where findings have converged or diverged. The CASP process allowed opportunity to assess the quality of the papers and give greater weight to methodologically robust papers, whilst appreciating the contribution of other research paper findings. Papers were re-checked to ensure there was information regarding the experience of the discharge process specifically addressed within the body of the paper. The decision was taken not to discard any papers on the basis of quality, as within qualitative literature, quality criteria and applicability are highly disputed (Mays and Pope, 2000). The overall quality of the studies was inconsistent. In some included studies, there was a lack of transparency in relation to theoretical approach, method and analysis. For the patient synthesis, only seven of the primary research studies included involved people living with cognitive impairment directly (Norman, 2003; Huby *et al.*, 2004; Emmett *et al*., 2014; Dyrstad, Laugaland and Storm, 2015; Boaden, 2016; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b).

2.4.5 Key factors impacting on the discharge experience for people living with dementia (patient synthesis)

Table 5. Key factors impacting on the discharge process for patients.

Table 5
Theme 1: Patient undermined from taking part in discharge planning and decision making
Subtheme: Family members replacing patient in the discharge decision making process
Subtheme: Hospital system undermining ability of patient to have agency during the discharge process
Subtheme: Health and social care staff member's actions preventing patient involvement in the discharge process
Theme 2: Privileging of hospital requirements above patient centred care
Subtheme: Rushed discharge processes due to hospital requirements
Subtheme: Unsafe discharge practices due to hospital pressures
Theme 3: Absence of resource, policy, and governance in the hospital discharge process
Subtheme: Deficiency in availability of community services
Subtheme: Lack of adopted discharge policy initiatives alongside ad hoc discharge planning

The synthesis process occurred separately for the two groups: people living with dementia and carers. Three key themes and seven subthemes emerged from the meta- ethnography as the key factors impacting on the discharge experience of people living with dementia. The key themes included the patient being undermined from taking part in discharge planning and decision making, the privileging of hospital requirements above patient centred care and the absence of resource, policy, and governance in the hospital discharge process. Detail regarding the themes and subthemes is included in table 5.

Subthemes included: Family members replacing the patient in the discharge decision making process; the hospital system undermining the ability of patient to have agency during the discharge process; health and social care staff members actions preventing patient involvement in the discharge process; rushed discharge processes due to hospital requirements; unsafe discharge practices due to hospital pressures; deficiency in availability of community services and a lack of adopted discharge initiatives alongside ad hoc discharge planning.

2.4.5.1 Theme 1: Patient undermined from taking part in discharge planning and decision making.

Family members replacing patient in the discharge decision making process.

It was identified in several studies that relative's opinions were prioritised by health and social care professionals, over the opinions of people living with cognitive impairment (Kadushin and Kulys, 1994; Norman, 2003; Digby, Lee and Williams, 2018a; Rhynas *et al.*, 2018).

> *'Often during the early part of an admission, the views of family members predominated in comparison with an absent voice of the older person. In many of the case records, this dominant "voice" was maintained in records of formal meetings and conversations between relatives and staff.'*
>
> (Rhynas *et al.*, 2018, p.6)

Rhynas *et al.* (2018) identified that relatives were often consulted about discharge decisions before patients, and that health and social care professionals were only inclined to listen to the views of people living with dementia if they corresponded with relative perspectives. Sometimes these decisions could be life changing for the patient. For example, Digby, Lee and Williams (2018a) identified that family members were applying for residential placements, at discharge for their relatives, and had not consulted them about this outcome.

> *'Bertha had been assessed by the neuropsychologist and deemed to be unable to make complex life decisions and therefore assessed as unsafe to return home. The team and the family had agreed that she needed permanent care. Not knowing what was going to happen but suspecting that*

> *residential care was being considered caused Bertha intense anxiety.'*
>
> (Digby, Lee and Williams, 2018a, p.75)

In accordance with this undermining of the patient, Kadushin and Kulys (1994) found that when patients had dementia, their involvement in the discharge process was often substituted for the involvement of their relatives by health and social care professionals (Emmett *et al.*, 2014). This can be problematic as it has been shown that family carers can have different discharge goals to patients (Emmett *et al.*, 2014; Poole *et al.*, 2014; Coleman and Roman, 2015).

> *'They shouldn't just look at the needs of the patient. They should look at the needs of the family ... if they are going to take the time to ask what are (the) goals of the patient ... then they should ask what do you need to have happen at home?'*
>
> (Coleman and Roman, 2015, p.15)

In contrast to the ways in which family involvement undermined patient involvement, some research (Dyrstad, Laugaland and Storm, 2015; Rhynas *et al.,* 2018) identified that adult children in particular could function as advocates for their relative and ensure that their opinion was represented during the hospital discharge process. Therefore, the involvement of relatives in the discharge process could have a positive or negative impact on the patient experience, dependent on whether the relative chose to act as an advocate or a replacement figure for the patient during decision making.

Hospital system undermining ability of patient to have agency during the discharge process.

The evidence identified that people living with dementia were often excluded from the discharge planning process, due to the nature of the hospital hierarchy which places the opinions of professionals above the opinions of lay members of the public, including carers (Kadushin and Kulys, 1994; Norman, 2003; Huby *et al.*, 2004; Emmett *et al.*, 2014; Telford, 2015; Gilmore-Bykovskyi, 2017; Digby, Lee and Williams, 2018a; Rhynas *et al.*, 2018). Findings identify that people living with cognitive impairment often feel powerless and unable to assert agency, during the hospital discharge process, particularly regarding identifying the discharge destination (Huby *et al*., 2004; Telford, 2015; Digby, Lee and Williams, 2018b; Rhynas et al., 2018).

> *'I asked her how she came in here. She said it was her leg. It would not bend. I asked her what she wanted. She wanted to go home. I asked her why she did not tell the doctor she wanted to go home. She said she could not tell them. 'It wouldna'e be rite'. Neither 'could she just tell them she was leaving'. I tried to ask her why not, but she could not explain. I asked if it was because they knew better, or because they had done things for her. She said it was because they had done things for her. I don't know if I put the idea to her and she just repeated it. I suggested that the nurse and doctors felt she would not be safe at home because she might fall like she had done earlier. She did not agree and said she felt she would be OK in her own home once she was settled. She told me that she had lost her husband 3 months ago, and that she was sure all this came from the shock. I asked if she had told anybody (in the hospital?) She said no, and that she could not tell them unless they asked her. I asked her if she knew what would happen now. She said she did not know.'*
>
> (Huby *et al*., 2004, p.119)

Kadushin and Kulys (1994) and Dyrstad, Laugaland and Storm (2015), identified that the paternalistic nature of the hospital system often excluded people living with dementia from discussions around discharge destination. Other researchers (Huby *et al.*, 2004) have suggested that the hospital system and process places people living with dementia in a passive position. For example, the nature of capacity assessments can undermine the agency of the patient with cognitive impairment (Norman, 2003; Poole *et al*., 2014; Digby, Lee and Williams, 2018a), as do the pre-eminence of formal assessments which exclude the subjective views of patients (Huby *et al*., 2004). Emmett *et al*. (2014) found that capacity assessments were often conflated with best interest decisions, and that capacity assessments were often used to undermine patient involvement in their discharge. Poole *et al* (2014) also identified this.

> *'I think at the moment we've kind of got stuck with thinking, Right, what do we ultimately want for this person…. There's the patient, that's what we want for the person and how do we get there, rather than going through a*

> *nice routine process. Um ...... I suppose every patient who came on this ward, for instance, if their capacity just now was assessed, regardless of what the outcome's going to be, it would show that we're actually doing it routinely, rather than just when we need to do it, because we want to make a decision that the person's not going to like.'*
>
> (Poole *et al*., 2014, p.7)

Further to this, it has been suggested that the inherently opaque system of the hospital discharge process makes it difficult for people living with dementia to understand, let alone challenge, the process or its outcome (Huby *et al.*, 2004). Safety considerations and the language of risk are identified in several research findings as undermining the patient with cognitive impairment's ability to be involved in the hospital discharge process (Kadushin and Kulys, 1994; Norman, 2003; Emmett *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b; Rhynas *et al.*, 2018).

> *'It depends on what stage their dementia is really. As to whether we can discuss the options with them. Because most people want to go home.*
>
> *They don't realise that they won't be safe at home.'*
>
> (Norman, 2003, p.136)

Rhynas *et al.* (2018) argued that patients with cognitive impairment are often objectified due to the language of risk, and that patient safety is often prioritised over the patient's right to make decisions (Kadushin and Kulys, 1994; Emmett *et al.*, 2014; Hall *et al.*, 2020). Redwood, Eley and Gaughan (2016) identified that once it has been decided by a medical professional that it is too risky to discharge a patient home, it is very difficult for other healthcare professionals or patients to challenge that decision. Further to this, Huby *et al.* (2004) identified that narrow definitions of risk and set procedures, guided by formal assessments, often lead to the undermining and exclusion of patients from the discharge decision making process. Hall *et al.* (2020) identified that safety concerns were placed above the requirement for physiotherapy and rehabilitation for people living with dementia at discharge. Conversely, Schreiber, Powell and O'Dowd (2018) identified that there are occasions when health and social care professionals prioritise the patient’s right to decide about going home over safety concerns.

> *‘Physio: . . . we found that she had what we call an AMT score of five out of ten which means quite a large amount of confusion, unsure how much, what input she’s going to remember from the previous day.*
>
> *Interviewer: So how much do you think Mrs B can be involved in making decisions about what happens to her when she leaves the hospital?*
>
> *Physio: She I mean she can be; she’ll be involved in input. Obviously, we’ll take inconsideration what she says but at the same time, we’ve got to remember that is she going to be safe going home with this or without this?’*
>
> (Huby *et al*., 2004, p.124)

> *‘On the other hand, if her discharge was delayed, Ms. X would have likely become more agitated. She might have required medications, possibly antipsychotics or benzodiazepines, to manage her agitation, which would have exposed her to their risks, up to and including death. Although there might have been some benefit to delaying her discharge to see if she would agree to another skilled nursing facility (snf) trial, the potential harms seemed to outweigh the benefits. Finally, to force her into a nursing home again seemed doomed to fail as she had already resisted both living with family and being discharged to a SNF. In weighing all of this information, the psychiatrist held Ms. X to a level 1 on Drane’s sliding scale of decisional capacity 17 and determined that she had residence capacity to refuse a SNF and to return home.*’
>
> (Schreiber, Powell and O'Dowd, 2018, p.616)

Therefore, overcoming the notion of risk appears a significant barrier to people living with dementia having agency in the hospital discharge process, but it is not an impossible obstacle and can be overcome dependent on the actions of health and social care professionals.

Health and social care staff member’s actions preventing patient involvement in the discharge process.

Health and social care staff actions were often identified as integral in the undermining of patients with cognitive impairment involvement in the discharge decision making process (Huby *et al.*, 2004; Norman, 2003; Telford, 2015; Rhynas *et al.*, 2018). Norman (2003) and Dyrstad, Laugaland and Storm (2015) recognised that patient perspectives were often left unacknowledged by health and social care staff.

> *Despite patients' objections and arguments of poor health, the decision to discharge patients was most often made by the professionals, with the patients being transferred to follow-up care in the municipality.*
>
> (Dyrstad, Laugaland and Storm, 2015, p.1702)

Further to this, some healthcare staff revealed, during interviews, that they believe people living with dementia are not able to make decisions in their own best interests during the hospital discharge process (Norman, 2003). The Department of Health and Social Care (2015) identified that prejudice amongst health and social care professionals prevented referral to services and care pathways connected to mobility. Huby *et al.* (2004) and Kadushin and Kulys (1994) found that health and social care professionals predominantly set discharge goals themselves, and a number of research findings identified that health and social care professionals regularly discussed discharge arrangements amongst themselves, without discussion with the patient with cognitive impairment (Norman, 2003; Huby *et al.*, 2004; Poole *et al.*, 2014; Dyrstad, Laugaland and Storm, 2015; Telford, 2015; Rhynas *et al.*, 2018). Further to this, Poole *et al.* (2014) found that health and social care professionals held the opinions and perspectives of colleagues in higher regard than patient opinions. This led to the undermining of the contribution of the patient to the discharge process.

> *'F: So, looking at maybe discharge plans, how much involvement do you think in your knowledge, do people with dementia have in their plans ... Is it possible to consult the person with dementia?*
>
> *S: Well with us, the only consultation they have is if we think oh bugger is this going to be EMI [Elderly Mentally Infirm unit] or EPH [elderly persons home], and then we get [name of Dr.] or one of his team to assess and they'll give us a "right he's going to need EMI" which they rarely say, they usually say "oh yes, EPH will be fine". And we say no. I mean that's usually the only input they get. Obviously if [Dr] says*

> *yes, they can't make their own decisions, fine, which invariably they don't which is quite reasonable really 'cos you're take away every single right they've got. Other than yes, I want to go home, that's about it.'*
>
> (Norman, 2003, p.139)

Although often unhappy with this, Huby *et al.* (2004) found during interviews with patients with cognitive impairment that they often felt uncomfortable challenging staff, even when excluded from decision making, as they felt they lacked the knowledge to challenge the hospital discharge process and didn't want to be seen as critical of individual staff members. A noted exception to this pattern was found by Telford (2015), who identified that health and social care staff were more open to collaboration with people living with dementia if the patient was to be discharged to a residential facility. Several other researchers also found that some health and social care professionals did support patient involvement in the discharge process (Poole *et al.*, 2014; Dyrstad, Laugaland and Storm, 2015), although this was not the normative finding. However, overall research findings suggest that health and social care staff regularly undermined the participation of people living with dementia in the discharge planning process. This often led to great anxiety and distress for patients during the hospital discharge process (Norman, 2003; Huby *et al.*, 2004; Telford, 2015). Nevertheless, an important caveat to consider was identified in research by Huby *et al.* (2004) and Poole *et al.* (2014), where it was discussed that some patients living with cognitive impairment identified that they would rather not be included in the discharge process and preferred health and social care professionals to make key decisions.

> *Interviewer: And what does the term . . . have you heard the term 'patient participation'—it's kind of like a jargon word that is going about. What would 'patient participation' mean to you as a term?*
>
> *Respondent: 'Not a lot to be honest. I a'ways say let them that's qualified for ta (to) dae (do) it get on wi' it' (Man, 65, Stroke Unit)*
>
> (Huby *et al.*, 2004, p.126)

2.4.5.2 Theme 2: Privileging of hospital requirements above patient centred care

Rushed discharge processes due to hospital requirements.

The privileging of hospital requirements above the needs of people living with dementia, during the hospital discharge process, was increasingly evident in relation to the need for hospital beds to be made available as soon as possible (Norman, 2003; Emmett *et al*., 2014; Dyrstad, Laugaland and Storm, 2015; Gilmore-Bykovskyi, 2017). People living with dementia were often reduced to their medical needs and diagnosis (Dyrstad, Laugaland and Storm, 2015; Telford, 2015; Kuluski and McGeown, 2017) and their non-medical requirements were ignored. Some research suggested that organisational hospital requirements were regularly prioritised above the needs of patients (Gilmore-Bykovskyi, 2017).

> *'To me it seems like sometimes the hospital just wants to dump the patients so to speak. Because they've got to get them out of there, and that's what they tell us all the time how they need beds, and they can't do anything for someone with dementia – they just need our long-term care. But then a lot of times it's completely different from what the social worker at the hospital tells our social worker."*
>
> (Gilmore-Bykovskyi, 2017, p.873)

Tight hospital schedules led to limited time for health care professionals to discuss discharge options with people living with dementia (Dyrstad, Laugaland and Storm, 2015). Due to the pressure to discharge people living with dementia, following the resolution of their medical conditions, it was found that some patients were discharged prematurely (Parliamentary Health Service Ombudsman, 2016) and that these premature discharges could lead to poor and unsafe discharge experiences for the patient (Gilmore-Bykovskyi, 2017). Further to this, Dyrstad, Laugaland and Storm (2015) identified that rushed discharge could often leave the patient struggling to remember and understand information provided on the day of discharge.

> *One son said (to the researcher on the phone): 'The discharge came very soon. They could have called a day*

> *before discharge'. The next of kin also picked up medications from the pharmacy; family members were sometimes observed to drive the discharged patient from the hospital to the nursing home, as they did not want the patient to take a taxi. According to one son of an 87-year-old woman with malnutrition, 'Cognitively impaired or not makes no difference. To include family is important. The older patients often do not remember and cannot answer questions about their own health conditions'.*
>
> (Dyrstad, Laugaland and Storm, 2015, p.1702)

Unsafe discharge practices due to hospital pressures

Unsafe discharges were identified in several reports and highlighted by case studies of individual experience for people living with dementia (Kable *et al.*, 2015). Cumbler, Carter and Kutner (2008) identified that pressure to free up bed space could lead to patients being discharged over a weekend, and this could be hazardous as services and staff usually available are often absent over a weekend period. Further to this, the Parliamentary Health Service Ombudsman report (2016) found multiple cases of people living with dementia being discharged overnight. This was identified as being a dangerous practice which could lead to an extremely poor discharge experience for the patient with cognitive impairment.

> *'Mrs K was transferred to the acute medical unit to wait for an ambulance. An ambulance was booked at 8.48pm; Mrs K's medical notes showed this was before she had expressed her preference to go home. It arrived at 11pm. Although the hospital had been unable to reach Mrs K's son to let him know that they planned to discharge his mother, it let Mrs K go home.*
>
> *The following morning Mrs K's daughter, Mrs G, visited her at home. She found that her mother had been left with no food, drink and bedding, unable to care for herself or get to the toilet.'*
>
> *Relative: 'Surely when family members have made their concerns 100% clear and a vulnerable, virtually immobile 93-year-old is sent home alone, something is very wrong somewhere.'*
>
> (Parliamentary Health Service Ombudsman, 2016, p.19)

2.4.5.3 Theme 3: Absence of resource, policy, and governance in the hospital discharge process

Deficiency in availability of community services

Huby *et al.* (2004), Emmett *et al.* (2014), Kable *et al*. (2015), and Kaiser and Kaiser (2017), identified that a deficiency in the services available, on discharge to the community, resulted in discharge destination being based on availability and not suitability. This lack of availability led to people living with dementia experiencing extended delays in the discharge process (Parliamentary Health Service Ombudsman, 2016). Telford (2015) and Kable *et al.* (2015) further identified that delays in discharge were often as a result of awaiting community placements, and that delayed discharge could be due to poor co-ordination across services in the community (Parliamentary Health Service Ombudsman, 2016).

> *'...a long waiting list for access to community physio, . . . day hospital, could be weeks. . . we've had people . . . waiting for up to 2 years ...if the service hasn't come after 30 days, they drop off that list and they're not in the system (DP group).'*
>
> (Kable *et al*., 2015, p.5)

Lack of adopted discharge policy initiatives alongside ad hoc discharge planning.

A number of studies identified that patients were often experiencing poor and ad hoc discharge planning, leading to discharge without a formal discharge plan, or with an untailored and inappropriate plan, resulting in anxiety for the patient during the discharge period (Bauer, Fitzgerald and Koch, 2011; Kable *et al*., 2015; Boaden, 2016; Jamieson *et al*., 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017).

> *'If... you could sit down (with each patient) and say this is why you were here, this is the plan when you leave, but it actually happens very rarely (JMO group).*
>
> (Kable *et al*., 2015, p.6)

Discharge summaries could be insufficient with no attention paid to social or dementia related needs, but only medical requirements (Kable *et al.*, 2015). One comprehensive report (Parliamentary Health Service Ombudsman, 2016) identified that hospitals were at times omitting to implement capacity assessments, leading to instances of deprivation of liberty for patients. There was also a noted lack of safeguarding occurring in many hospital discharge processes for people living with dementia (Cumbler, Carter and Kutner, 2008; Boaden, 2016; Jamieson *et al.*, 2016; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016).

> ‘*After a 2 week stay, the hospital decided to discharge him on the Thursday before the August Bank holiday weekend, when support was not available until the next Tuesday because of the holiday. It was at home that the wife discovered that, as well as being incapacitated with a broken hip, her husband was doubly incontinent – she couldn’t cope. After a day the out-of-hours doctor advised her to take her husband to A&E. She had to leave him there to look after her autistic son. The husband called to say he was being discharged. The wife refused to bring him home because he couldn’t walk, and he was admitted onto a ward.’*
>
> (Macmillan, 2016, p.194)

Multiple reports revealed that people living with dementia are at risk of being discharged to their home address with no heating, food, care packages, family support or access to toilet facilities (Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016). Bauer, Fitzgerald and Koch (2011) reported an instance of a patient being discharged home with an injury which had gone unnoticed, suggesting a worrying absence of people living with dementia being safeguarded at discharge. Further absences of safeguarding are evident, specifically around medication provision at the point of discharge (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kable *et al*., 2015; Deeks *et al*., 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017).

> *‘At 5 pm with 3 pages of discharge medications, new initiations of warfarin. they are actually really unsafe discharges. (#4 hospital pharmacist)’*
>
> (Deeks *et al*., 2016, p.453)

Numerous studies found that people living with dementia were discharged home or to residential facilities without medication, or with the wrong medication (Cumbler, Carter and Kutner, 2008; Kaiser and Kaiser, 2017). Deeks *et al.* (2016) found that there was often a lack of information around medication schedules, or changes implemented in the hospital context, communicated to care providers and community services at the point of discharge. This was found to lead to multiple medication errors during the transitionary discharge process (Kaiser and Varghese, 2014). It was identified that people living with dementia were often discharged from hospital without the correct assessments being completed and without social service involvement (Boaden, 2016; Parliamentary Health Service Ombudsman, 2016). Another issue caused by ad hoc discharge planning was the prevalence of long waiting periods for transport home or to residential placements. Telford (2015) identified that multiple patients with cognitive impairment experienced the day of discharge itself as a taxing experience, due to being delayed, due to a dearth of available discharge transport.

> *Frederick: Of course, she was getting distressed. I was getting angry.*
>
> *Clive: [It was a] bit stressful, because [we were] waiting a long time for an ambulance … we waited nearly the whole day for her [my wife] to arrive.*
>
> (Telford, 2015, p.111)

This synthesis has identified the experiences of people living with dementia of the hospital discharge process. In the next section, the synthesis of carer experiences will be presented, beginning with the key factors that emerged from the meta-ethnography.

2.4.6 Key Factors impacting on the discharge experience for carers of people living with dementia (carer synthesis)

Table 6. Key factors impacting on the discharge experience for carers of people living with dementia (carer synthesis)

Table 6
Theme 1: Carer experience of being included in the discharge process.
Subtheme: Experience of being included in the discharge planning process (positive aspects)
Subtheme: Experience of being included in the discharge planning process (negative aspects)
Theme 2: Experience of being excluded from the discharge planning process
Subtheme: Not being treated as an expert in the care of the person living with dementia
Subtheme: Recipient of ineffective communication
Theme 3: Requirement for further robust support during discharge process
Subtheme: Unmet need for support for carer navigating the discharge process

The synthesis of the experience of the hospital discharge process for carers revealed three main themes. These included: **the experience of being included in the discharge process; being excluded from the process; and a requirement for further robust support**. Five subthemes were identified including: the positive and negative aspects of being included in the discharge process; not being treated as an expert in the care of the person living with dementia; being the recipient of ineffective communication, and the unmet need for support for the carer navigating community services. Further information relating to the themes and subthemes is included in table 6.

2.4.6.1 Theme 1: Carer experience of being included in the discharge process.

Experience of being included in the discharge planning process (positive aspects)

For carers, the hospital discharge can be experienced as an empowering process when it occurs in partnership with health and social care professionals (Cox, 1996). Good communication between family carers and professionals can enable a constructive discharge experience and ensure positive discharge outcomes for both the patient and their family (Gupta *et al.*, 2006; Fitzgerald *et al.*, 2011; Emmett *et al.*, 2014;).

> *'Mrs Baker was 88 and prior to her admission to hospital lived in her own bungalow with the help of professional carers and her family who lived locally. She was admitted to hospital with a UTI and was assessed as being on the borderline of lacking capacity to decide where she should live. The professional decision to discharge Mrs Baker home was facilitated in no small part by her family's tenacious and persistent questioning of hospital professionals and their familiarity with hospital processes.'*
>
> (Emmett *et al*., 2014, p.314)
>
> *'Well, there was quite a bit of information given to me and a lot of the services that I could expect after she came back home, that was all arranged by the welfare people, [which began] during the whole four weeks. I remember the relevant people in the welfare department [saw me] and they would give me some information. And a couple of times I was actually in an office, invited to talk with someone in the office, and quite a bit of information was given to me. I'm quite happy with what was provided. [John, husband].*
>
> (Fitzgerald *et al*., 2011, p.367)

Ensuring productive relationships with key professionals, such as pharmacists (Coleman and Roman, 2015), involving family members with an understanding of the health and social care system (Emmett *et al.*, 2014) and the presence of collaborative partnership working within the health and social care professional multi-disciplinary team (Jamieson *et al.*, 2016) have been identified as integral to a positive and timely discharge experience (Gupta *et al.*, 2006). Further to this, continuity in the professionals involved in the discharge process was identified as crucial to ensuring a positive experience for carers (Rhynas *et al.*, 2018).

Formal discharge planning meetings allowing carers an opportunity to share their concerns, opinions and granting agency for involvement in decision making, was identified by several studies as integral to enabling a positive hospital discharge experience (Cox, 1996; Gupta *et al*., 2006; Rhynas *et al.*, 2018). The plan to discharge into a care home setting also appeared to improve collaboration between professionals and carers (Cox, 1996; Telford, 2015) along with the presence of a formal ‘title’ for the carer, such as holding power of attorney (Coleman and Roman, 2015).

> ‘*Several family carers suggested that family titles (i.e., daughter or spouse) seemed to garner more respect from health professionals. Others made reference to the importance of being identified in a functional role such as healthcare power of attorney.*’
>
> (Coleman and Roman, 2015, p.18)

However, several studies identified that good practice appears to be linked to local champions, local networks and individual good practice (Cooper and Deeks, 2012; Deeks *et al.*, 2016) rather than policy or process led systems. The good clinical practice enabled by positive communication, settings which enable shared decision making and inter-professional working practices, appears relatively infrequently in the included studies, in comparison to the focus on the negative experiences of carers being excluded from the discharge planning process, or the negative experiences connected with being involved in the hospital discharge.

Experience of being included in the discharge planning process (negative aspects)

Although carer involvement in the discharge planning process can be a positive experience, a range of negative aspects to involvement were identified in the studies. Being involved in the discharge planning process has been identified as potentially having a negative impact on a carer’s mental health (Macmillan, 2016). A number of the included studies identified that challenges encountered as part of the discharge process caused anxiety, exhaustion and stress, and significant disappointment at the mismatch between their expectations, and the reality of the discharge process (Cox, 1996; Jamieson *et al.*, 2016; Sanatinia *et al.*, 2020).

> *'I can't handle this anymore; I'm absolutely buggered from no sleep at all, all night*.' (Partner)
>
> (Jamieson *et al.*, 2016, p.862)

Carers appear to experience stress or frustration in relation to; interactions with health and social care professionals (Telford, 2015); worries in relation to finance and funding around care packages (Mockford *et al.*, 2017); poor service delivery (Mockford *et al.*, 2017); feeling judged in relation to their caring abilities by professionals (Jamieson *et al.*, 2016) and poor documentation (Kable *et al.*, 2015), with the day of discharge being acknowledged as a particularly anxious period (Telford, 2015).

> *'Some carers worried about how to pay for the cost of social care at home in the future.'*
>
> (Mockford *et al.*, 2017, p.502)

Jamieson *et al.* (2016) identified that carers often experience exhaustion at the lack of co-ordination within the hospital discharge process. In answer to this, Coleman and Roman (2015) found that carers try to take on the coordinating role themselves and find navigating this both challenging and frustrating. A significant source of emotional conflict for carers is in relation to care home placement on discharge for the patient. Multiple studies identified how conflicted carers feel in relation to hospital discharge to care home locations (Kadushin and Kulys, 1994; Cox, 1996; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). Many carers experience feelings of guilt, grief and depression (Cox, 1996; Bloomer *et al*, 2016) and will struggle to ensure that their relative is discharged home, even if this is potentially inappropriate, particularly if the person living with dementia is a parent (Bloomer *et al*, 2016; Rhynas *et al.*, 2018). Being involved in the decision to admit the person living with dementia to a care home was identified also have a negative impact on wider family relationships for the carer (Bloomer *et al*, 2016) compounding the impact on their mental health.

> *'It's a different thing when Mum was living with us. He just didn't handle things, and I was between the devil and the deep. I didn't want to - Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly.'*
>
> (Bloomer *et al*, 2016, p.907)

2.4.6.2 Theme 2: Carer experience of being excluded from the discharge planning process.

The included studies identified that being excluded from the discharge planning process was a central facet to the hospital discharge experience for carers, with a minority of hospitals having a system for including relatives formally in the process (Emmett *et al.*, 2014; Dyrstad, Laugaland and Storm, 2015). The experience of being excluded can be broadly divided into two aspects: not being treated as an expert in patient care; and being the recipient of ineffective communication.

Not treated as an expert in the care of the person living with dementia

Several studies identified that not being treated as an expert in patient care was central to many carers hospital discharge experience (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016). Habitually, carers are not invited to discharge planning meetings (Dyrstad, Laugaland and Storm, 2015), and even if invited they are not given warning about the topics to be discussed, or adequate time to think through the decisions to be made (Emmett *et al.*, 2014). Carers identified that they do not feel involved in decision making (Mockford *et al.*, 2017) and do not feel that the discharge process itself is collaborative (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016).

> *'Sometimes it was a bit frustrating to try and find who's looking after her and where is that person... unless you actually caught somebody at the bedside, we didn't have a lot of information. (Daughter)*
>
> *I would have liked to have one person I could go to. They [the hospital] didn't have anybody that I could just say well, I'll ask the question of this person... I just didn't get the communication happening.... (Husband)*
>
> (Bauer *et al.*, 2011, p.320*)*

Carers argued that they felt ‘unheard’ (Coleman and Roman, 2015; Telford, 2015) and that their unique knowledge of the patient was not sought by health and social care staff. Carers identified feeling disempowered by the health and social care team and being unaware of the actions and decisions occurring in relation to the discharge process (Bloomer *et al*, 2016). Emmett *et al.* (2014) identified that social care professionals referred to written medical notes to aid decision making and did not elicit the opinions of carers.

> *‘And even the second time, … even then it was still negative, you know; ‘Well I’m concerned about such and-such, and such-and-such’; no interest in the whole patient; it’s just, I’ve got this information from the documentation and I’m going to read it out for you.’*
>
> (Poole *et al*., 2014, p.10)

Similarly, Coleman and Roman (2015) found that discharge goals were set by health and social care professionals and not by carers. Further to this Emmett *et al.* (2014), found that medical knowledge was often used to undermine the opinion and perspective of the carer. Being involved in discharge meetings was, at times, referred to by professionals to, ‘manage carer expectations.’ The implications of this are not indicative of a collaborative discharge process (Sanatinia *et al.*, 2020).

Predictably, the exclusion of carers from the decision-making process meant that multiple studies identified that health and social care professionals make discharge decisions amongst the multi-disciplinary team and community services only (Dyrstad, Laugaland and Storm, 2015; Telford, 2015). Where carers were involved in discharge planning and decision making, it was in a superficial manner (Kadushin and Kulys, 1994). An example was identified in Kuluski and McGeown (2017), where carers were able to choose the long-term placement destination for their relative but were unable to have any influence over when or how the placement would begin. Carers identified feeling powerless (Telford, 2015) or undermined (Emmett *et al.*, 2014) in their interactions with health and social care professionals and struggled to influence discharge decisions (Emmett *et al.*, 2014). The absence of a formal discharge plan exacerbated the feelings of being unable to have agency in the discharge process (Fitzgerald *et al.*, 2011).

> *‘Yeah. Well, they seemed to be very pushy in, you know, getting him out of there, out of the [hospital]. I guess they needed the beds or something. And he [her son] says, “Mom, I think we’ve been railroaded.” We didn’t like the way it was going. They were suggesting that he come home. And we said no because I don’t know if I could cope with that and I think it would have been too much for me.’*
>
> (Kuluski and McGeown, 2017, p.5)

This experience of exclusion led to many carers reporting a difficult relationship with health and social care professionals (Bauer, Fitzgerald and Koch, 2011). Professionals not valuing carers as a resource, and the inherent power imbalance within interactions (Telford, 2015), created distrust within the therapeutic relationship. Carers reported feeling frustration and resentment towards professionals involved in the discharge process, particularly when professionals displayed a lack of training, or knowledge of the needs of people living with dementia (Mockford *et al.*, 2017).

> *‘Dealing with Mum’s incontinence . . . I said to them about taking her to the toilet every so often and I proved it to them on the home visit . . . The Occupational Therapist said ‘‘Do you want to go to the toilet Anne?’’ and I said, ‘‘No, no, no, no, you’re not listening!’’ I said, ‘‘just take her there!’’ So I steered her there. I got them to do it for about three more times during the day—‘‘Oh this is working—we’ve got no wets [incontinence].’’ The next day I go back and it’s all reversed!’ (Daughter)*
>
> (Bauer Fitzgerald and Koch., 2011, p.12)

Recipient of ineffective communication

One of the universal features of the carer experience, identified across multiple studies, was being the recipient of ineffective communication (Bauer *et al.*, 2011; Fitzgerald *et al.*, 2011; Emmett *et al.*, 2014 Sewter, 2014; Telford, 2015; Bloomer *et al*, 2016; Boaden, 2016; Deeks *et al.*, 2016; Mockford *et al.*, 2017). This was in relation to both communication between health and social care professionals and carers (Bauer, Fitzgerald and Koch, 2011; Fitzgerald *et al.*, 2011), and between organisations and professionals themselves (Sewter, 2014). Carers experienced ineffective communication in multiple settings (Deeks *et al.*, 2016) and in relation to a range of services, processes, and care needs (Mockford *et al.*, 2017). Carers identified that there was a lack of clear hospital policies in relation to communication with family carers (Bauer *et al.*, 2011), and experienced occasions where information was only communicated to the patient living with dementia (Dyrstad, Laugaland and Storm, 2015). This ineffective communication was identified as being culpable for the breakdown of service provision (Bauer, Fitzgerald and Koch, 2011).

> '*I would like just to be kept informed about what's happening. Certainly, kept informed if there are any ideas, that maybe she won't be able to continue the kind of care that she's been getting— those sort of things. You need to know what's going on.' (Daughter)*
>
> (Bauer, Fitzgerald and Koch, 2011, p.11).

Carers identified the absence of effective signposting (Bauer *et al.*, 2011; Emmett *et al.*, 2013; Emmett *et al.*, 2014) as a problem. Multiple studies highlighted that obtaining information was far from a straightforward process for carers, who found it difficult identifying who to approach within the health and social care team, for information about their relative (Bauer, Fitzgerald and Koch, 2011). Many studies identified that only when carers were particularly pro-active in ringing the ward, and approaching health and social care team members, did they believe they had experienced effective communication (Dyrstad, Laugaland and Storm, 2015; Kaiser and Kaiser, 2017).

Ineffective communication as a problem presented itself throughout the discharge process. Carers were often not provided with clinical information at the point of discharge (Bauer *et al.*, 2011; Emmett et al., 2013; Emmett *et al.*, 2014) including the results of diagnostic tests (Kaiser and Kaiser, 2017). Carers were often not provided with information about the discharge day or time, leading to potentially dangerous scenarios (Boaden, 2016; Macmillan, 2016).

An example of a common scenario was identified in Bauer, Fitzgerald and Koch (2011, p. 1)

> *'They were saying, 'we're planning to put her in a taxi and send her home.'' And I said, ''You can't do that, she's got dementia. She'll be really disoriented, and she hasn't even got a house key.'*

Sometimes carers identified relatives being discharged at the weekend without warning (Cumbler, Carter and Kutner, 2008), or being given very short notice for a same day discharge (Dyrstad, Laugaland and Storm, 2015; Jamieson *et al.*, 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017). The importance of timely discharge planning was highlighted by a number of carers (Fitzgerald *et al.*, 2011; Shippen, Young and Woods, 2011) as central to ensure a safe and effective discharge process. It was also highlighted that being physically present on the ward ensured more robust discharge planning and safeguarding (Fry *et al.*, 2022).

Insufficient information and advice in relation to medication administration was reported by many carers across the studies (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Sawan *et al.*, 2021). Not having changes to medication regimes explained (Deeks *et al.*, 2016) or not being provided with medication at the point of discharge (Cumbler, Carter and Kutner, 2008), were highlighted as problematic. Coleman and Roman (2015) and Sawan *et al.* (2021) argued that carers often feel overwhelmed by the medication administration schedule. Kable *et al.* (2015) found that both the dosage and the administration timetable were not clearly explained to carers, leading to confusion and anxiety.

> '*She [care receiver] is taking too many kinds of medications. This morning, I planned to prepare all the medications for this week and put them into separate bags according to the meals they are taken with, but I could not do it because it is so confusing,'*
>
> (Shyu, 2000, p.622).

Further to this, Deeks *et al.* (2016) identified that an absence of sufficient communication with community pharmacies, regarding medication changes, also caused difficulties for carers post-discharge in the community. There was also insufficient communication for carers, both before and during the discharge process, in relation to caregiving skills and abilities (Shyu, 2000;

Levine, 2002; Bauer, Fitzgerald and Koch, 2011). Several studies highlighted that despite carers expressing a desire to experience training in relation to carer skills before discharge (Levine, 2002), health and social care staff are neither teaching these skills (Kaiser and Kaiser, 2017), nor assessing the carer's ability to provide care before discharge (Parliamentary Health Service Ombudsman, 2016).

> *'They described the lack of training in complex medical equipment that they were responsible for operating at home. What training was provided was perfunctory and dismissive of their fears.'*
>
> (Levine, 2002, p.175)

This often led to carers feeling unprepared for their role as carers following the discharge process (Coleman and Roman, 2015). In addition to feeling that they were unprepared for their carer role, carers also reported not being informed about available community support services or how to access them (Mockford, 2015; Shyu, 2000). Carers identified that there was a lack of co-ordination between hospitals and community services and care providers and requested that it would be beneficial for ward staff to arrange community services before their relatives exit the hospital setting (Shyu, 2000).

The prevalence of poor communication experiences is unfortunate, as several studies (Shippen, Young and Woods, 2011; Gupta *et al.*, 2006) found that carers felt empowered and supported during the discharge process by experiencing good communication. Moreover, a formalized setting where discussions could take place between the carer and health and social care team, and formulate a formal discharge plan, enabled the carer to manage the discharge process more effectively than where no formal process is available (Gupta *et al.*, 2006).

2.4.6.3 Theme 3: Requirement for further robust support during discharge process

Unmet need for support for carer navigating the discharge process.

Carers reported a deficiency in the support available from health and social care services and individuals, during the hospital discharge process (Bauer, Fitzgerald and Koch, 2011; Coleman and Roman, 2015; Kuluski and McGeown, 2017). Numerous studies identified that while there is support available for carers, it does not appear to be woven into the fabric of the discharge process itself, and carers are often unaware of its existence (Coleman and Roman, 2015; Kuluski and McGeown, 2017). Carers felt that there was a deficiency in the emotional support available (Kadushin and Kulys, 1994; Shyu, 2000; Jamieson *et al.*, 2016) and identified that a service to support their mental health would be helpful (Shyu, 2000). The emotional struggle many carers experienced was evident.

> *'I am under a lot of pressure, long-term pressure. I need someone to talk to, to dump my garbage and an outlet for my emotional pressure.'*
>
> (Shyu, 2000, p.623)

Carers reported experiencing the discharge process as rushed, with little time to absorb new information or being supported to contribute to decision making (Kaiser and Kaiser, 2017; Dabelko-Schoeny *et al.*, 2020). Several studies identified that this rushed process often led to medication errors (Kaiser and Varghese, 2014; Coleman and Roman, 2015) and the discharge plan being dictated to carers, rather than being developed in a collaborative manner (Telford, 2015).

Carers identified that their needs were often overlooked in favour of the patients' needs (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016) or the requirements of the hospital system (Parliamentary Health Service Ombudsman, 2016; Kuluski and McGeown, 2017).

> *'I'm thinking ''What am I going to do? How am I going to manage this?'' Well really, getting the right information and obviously when - see, they're only working on him, and they got to work on the family'.*

(Bloomer *et al*, 2016, p. 310)

Carers were not asked whether they felt confident to continue in a caring role (Bloomer *et al*, 2016), and some carers (Kuluski and McGeown, 2017) reported feeling pressured to facilitate the return home of the patient living with dementia, before a long-term care plan was in place, to ease pressure on the ward. One carer reported begging ward staff not to discharge her husband, as she felt she could not manage his care requirements (Parliamentary Health Service Ombudsman, 2016). Further to this, the carer reported that she was not assessed in relation to her ability to provide care or whether she owned the correct equipment to provide the necessary care to her husband (Parliamentary Health Service Ombudsman, 2016). This failure to consider the needs of carers was identified as having a negative impact on the mental health of the carer themselves (Bloomer *et al*, 2016).

Complexity of navigating community services

Carers consistently reported issues relating to the complexity of navigating community services both during and after the hospital discharge process (Parliamentary Health Service Ombudsman, 2016). Carers reported this was made more difficult by the lack of co-ordination between health and social care systems (Parliamentary Health Service Ombudsman, 2016), including a dearth of information sharing (Shippen, Young and Woods, 2011) and communication (Gilmore-Bykovskyi, 2017). This is further exacerbated by local authority boundaries adding to confusion around which services are available to carers (Jamieson *et al.*, 2016).

Many carers reported a delay in services starting in the community, leaving carers to try and manage patient care needs alone upon discharge (Jamieson *et al.*, 2016). Others reported either a lack of affordable and available resources (Emmett *et al.*, 2013; Kable *et al.*, 2015) or inconsistent access to both GP and community services (Kable *et al.*, 2015; Jamieson *et al.*, 2016). Across the studies, it was often acknowledged that the services and resources available in the community did not meet the needs of carers (Bauer, Fitzgerald and Koch, 2011) and this entailed that discharge plans were often inadequate (Mockford *et al.*, 2017).

> *...a long waiting list for access to community physio, . . . day hospital, could be weeks. . . we've had people . . . waiting for up to 2 years ...if the service hasn't come after 30 days, they drop off that list and they're not in the system. (DP group)*
>
> (Kable *et al*., 2015, p.6)

Inflexible care arrangements via care agencies, and last-minute changes in care service availability, were identified as causing a lot of stress for individual carers (Mockford *et al*., 2017). Further to this, Mockford *et al*. (2017) identified that inexperienced care workers, and poor-quality interactions with care agencies, exacerbated the problems experienced by carers. Many reported experiencing fragmented services and identified significant gaps in the provision of community care support, leading to further experiences of emotional distress for the carer (Jamieson *et al.*, 2016).

When services aimed at both individuals living with dementia and their carers were available, gaining access was often challenging (Kable *et al.*, 2015; Jamieson *et al*., 2016). Long waiting periods were experienced for vital physical and emotional support services, including respite (Kable *et al.*, 2015), with carers expected to fill in the gap in care provision. Sometimes access to GPs was limited, (Deeks *et al.*, 2016) as was access to support groups and networks. This is particularly problematic as community carer networks and support groups have demonstrated the ability to provide emotional, and informational support, for carers following the discharge process (Jamieson *et al.*, 2016).

> *'Being able to compare notes and talk about what services are available, the other members of the group often know about things... support that I don't. It's good to share; if you didn't laugh sometimes, you would just cry. Alzheimer's is a cruel disease. (Daughter 4)*
>
> (Jamieson *et al.*, 2016, p.901).

Many of the carers identified that the reason they found navigating community services highly challenging was due to an undeveloped or even absent discharge planning process (Bauer, Fitzgerald and Koch, 2011; Sewter, 2014; Jamieson *et al.*, 2016). Carers identified there was often no formal discharge plan available (Bauer *et al.*, 2011), due to the pressure to discharge from the hospital into the community quickly (Gilmore-Bykovskyi, 2017). This absence of a discharge plan meant that there was no road map available to guide carers, the presence of which may have enabled a more effective discharge process (Shippen, Young and Woods, 2011; Mockford *et al.*, 2017).

> *'Well, it would be nice if you were told . . . have advanced notice, so you can plan to do things. It would be good to have at least one or two people you knew you could talk to each time to get feedback on whether or not she could come home or not. Obviously, one would like to be told . . . so that you could do the right thing.' (Daughter)*
>
> (Bauer, Fitzgerald and Koch, 2011, p.13)

A few studies identified that a mutually agreed, formal discharge plan (Mockford *et al.*, 2017) with shared, identified goals (Shippen, Young and Woods, 2011) led to a positive discharge experience for carers. Planning in a timely manner for discharge, with carers aware of the discharge timeline, also facilitated a positive experience, and opportunity for carers to ask questions and make their own requirements known (Gupta *et al.*, 2006). Moreover, a discharge communication clinic which facilitated discussion, between health and social care services and carers, and organized formal meetings, was shown to enhance the hospital discharge experience immensely (Gupta *et al.*, 2006).

2.5 Discussion of patient and carer synthesis

The findings of the patient synthesis reveal that many people living with dementia have a negative experience of the hospital discharge process. This is due to being undermined from taking part in discharge planning and decision making, due to the actions of family members, health and social care professionals and the hospital system. Considerations of risk particularly undermine the agency of people living with dementia. Further to this, it is evident that hospital requirements are often privileged above person centred care, leading to rushed and unsafe discharge practices. The potential absence of resource, policy and governance in the hospital discharge process is often problematic and has a negative impact on the patient experience. A lack of community resources and formal discharge policies and plans are shown to lead to negative outcomes for the patient, particularly around safeguarding.

Carer experiences of the discharge process have many similarities with the experiences of people living with dementia, but there are also significant differences evident. Carers experience deficiencies in communication and exclusion from the discharge planning process, poor discharge planning, and rushed discharge processes due to hospital considerations being prioritised above the needs of people living with dementia. However, carers are often responsible for navigating community services, and the key processes of the discharge itself, on behalf of the person living with dementia. Carers are also placed into a secondary position within the discharge process, and report frequently finding their needs overlooked or undermined during discharge planning. The experience of carers and people living with dementia of the discharge process may be similar, but their requirements for support are different resulting from their different roles within the process. Jamieson *et al.* (2016) has argued for a policy requirement to substantively support carers, alongside people living with dementia, to ensure that they receive the correct training and support before the discharge process is executed. A requirement for a shift in focus to ensure a discharge process more aware of the carer experience emerges from a few of the studies, and a need for a formalised discharge process (Fitzgerald *et al.*, 2011; Mockford *et al.*, 2017).

A significant proportion of the literature addressing the hospital discharge experience for people living with cognitive impairment, focuses on their involvement, or lack of involvement in the discharge planning process (Kadushin and Kulys, 1994; Huby et al., 2004; Dyrstad, Laugaland and Storm, 2015). This is also true of the carer synthesis (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). This prevalence is reflected in the themes identified during the meta- ethnography process and reveals the key focus of much of the research previously undertaken in this area.

Additionally, the research papers included in the review often focus upon negative experiences described by participants (Norman, 2003; Telford, 2015). This may be due to selection bias as many of the papers have a focus on improving the hospital discharge process and may be actively aiming to identify areas for improvement, rather than examples of good practice. The synthesis identified that there is limited evidence available about the factors that ensure a positive discharge experience for the patient living with dementia. This has also been identified by Shippen, Young and Woods (2011). This omission must be addressed in future research to ensure that the experience of people living with dementia is available to policy makers, medical and nursing staff, and to guide everyday ward practice and evidence-based discharge policies.

It was identified that a greater proportion of the research available addressing the topic of hospital discharge is focused on the carer experience (Bauer *et al.*, 2011; Coleman and Roman, 2015; Jamieson *et al.*, 2016; Kuluski and McGeown, 2017). This may be due to the difficulties, surrounding capacity and informed consent, inherent in research involving people living with cognitive impairment (Kuluski and McGeown, 2017). However, most people living with cognitive impairment are capable of involvement in research studies, if the provisions of the Mental Capacity Act (Department of Health, 2007), or national equivalent are adhered to. The absence of opinion from people living with dementia from studies exploring hospital discharge is concerning. It suggests that their experience and views are underrepresented, in favour of the views of carers and family members, who may have different perspectives and needs during the discharge procedure. Further research which includes people living with dementia is required to address this gap in the evidence base and enable nursing and medical staff to develop a better understanding of the needs of people living with dementia during the discharge process. This was a priority of this research project but was not possible during the empirical data collection period during the pandemic.

An interesting juxtaposition lies in the contrast between the significant focus on risk assessments during the discharge planning process (Kadushin and Kulys, 1994; Emmett *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b; Rhynas *et al.*, 2018), and an identifiable lack of safeguarding apparent during the discharge process (Cumbler, Carter and Kutner, 2008; Kaiser and

Varghese, 2014; Kable *et al.*, 2015; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). The two processes are vital to patient safety but appear to be given unequal attention during the discharge process. This contrast may highlight that once a patient leaves the hospital setting, health and social care professionals feel that they are no longer their responsibility, but the responsibility of a community-based service. As the hospital discharge progression should be viewed as one ongoing process (Redwood, Eley and Gaughan, 2016), this perspective should be challenged to ensure that the patients view of the discharge process is privileged during the hospital discharge process. Furthermore, clinicians must ensure that safeguarding concerns are sufficiently addressed before the patient is discharged. The adoption of a more person-centred approach to the discharge process may facilitate this, as this approach has been shown to be successful in other ward-based practice areas (Clissett *et al*., 2013). Further research into this topic is required. During the updated search in April 2022, one of the findings emerging from the research conducted by Fry *et al.* (2022) was the importance of the physical presence of a carer, during the discharge process, to safeguard the wellbeing of the person living with dementia. This finding has significant meaning in the post- pandemic climate, due to the physical absence of carers during the discharge process in the pandemic context.

The exclusion of the patient and the carer from decision making processes (Norman, 2003; Emmett et al., 2014; Telford, 2015; Rhynas *et al.*, 2018) must be challenged to support the patient to take part in discharge planning. This is vital to preventing patients being undermined, and omitted from the process, through the paternalism of the hospital system, or being replaced by relative involvement. This is especially important as the synthesis revealed that relative and carer involvement can have a positive or negative impact on patient experience (Emmett *et al*., 2014; Coleman and Roman, 2015; Dyrstad, Laugaland and Storm, 2015; Rhynas *et al.*, 2018). Clinical staff must be supported in this by hospital policy and procedures that support patient agency. However, it was revealed that some patients do not want to be involved in the decision-making process. This contrasting finding reveals the importance of ensuring that the preferences of each individual patient with cognitive impairment are considered during the discharge planning process, as there may be a variety of preferences for involvement in the hospital discharge process.

It is evident that clinicians must feel able to challenge unsafe practices that privilege hospital requirements and hierarchies but leave the patient at risk. Alongside this, community resources and hospital discharge policies that enable positive and safe hospital discharge practices must be available (Huby et al., 2004; Kable *et al.*, 2015; Kaiser and Kaiser, 2017). Without these resources health and social care professionals will continue to struggle in their support of people living with dementia during hospital discharge.

Gaps in the evidence base for people living with dementia and their carers include looking at positive experiences of the hospital discharge process and what facilitates this, wellbeing and how it can be supported during the discharge process by nursing staff and interventions which can improve the experience of discharge for people living with dementia. Significant further research is required which includes people living with dementia as participants.

Reflecting on the findings of both the patient and carer synthesis, reveals that this study's focus on wellbeing addresses a significant gap apparent within the evidence base. The concept of wellbeing has not been investigated within this context, and previous studies have often focused narrowly on the notions of inclusion or exclusion with the decision-making process. The often- negative experiences identified, with the acknowledgement that there may be some negative bias within the data collection process, illuminate the context in which this research study takes place. The synthesis suggests that there is a significant requirement for research which focuses on how to maintain wellbeing, for people living with dementia and their carers, during this process to enable the fulfilment of future changes in policy and practice that will counteract current poor experiences.

The absence of any qualitative evidence regarding the impact of COVID 19 on the hospital discharge process for people living with dementia, also reveals the importance of the data from the study, and its ability to reveal how people living with dementia and their carers, experienced the discharge process during the pandemic. Being able to access this information will enable policy makers and clinicians to understand the impact of the pandemic and adopt policies which would lessen the impact of any future pandemic conditions. It is unfortunate that the study cannot further the evidence base, regarding the experience of people living with dementia, with data obtained from those individuals themselves. This was not possible during the COVID 19 pandemic due to the social distancing legislation and the limits of technology.

2.5.1 Limitations and strengths of the systematic review process

The involvement of two reviewers in the screening process is identified as a strength of the review process as decisions relating to inclusion were discussed in a series of meetings between the reviewers. The agreement between the reviewers meant that there was no need for further review of the studies included. However, the extraction and synthesis was completed by one reviewer (LP). The systematic review process would have been strengthened by the inclusion of a second reviewer. Only studies in English were included in the review. Therefore, relevant studies in other languages may have been missed.

2.5.2 Limitations of and strengths of included studies

Several studies involved only isolated case studies which are indicative of the experience of people living with dementia but are not comprehensive enough to fairly represent patient experience (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). Several of the studies included only a small number of participants, and only 7 of the primary research studies involved people living with cognitive impairment directly. However, a few of the included studies involved in depth and rich data analysis of interviews or ethnographies of people living with dementia, and this represents a strength of the included studies and subsequent findings (Emmett et al., 2014; Dyrstad, Laugaland and Storm, 2015; Digby, Lee and Williams, 2018b).

2.5.3 Factors that should guide health and social care professionals in their support of wellbeing during the hospital discharge process for people living with dementia.

It is clear from the findings of the meta-ethnography synthesis that health and social care professionals are advised to:

- Ensure that discharge planning discussions include people living with dementia, and not only their relatives, to avoid the experience of anxiety and distress for excluded patients.
- Prevent considerations of risk from dominating hospital discharge decision making.
- Work to ensure that discharge goals are formulated with patients and carers and not solely by health and social care professionals in isolation.
- Be empowered to take responsibility for challenging premature or unsafe discharge practices, which prioritise the needs of the hospital above those of the patient.
- Take further responsibility for the day of discharge, including the provision of the correct medication for the patient, to prevent post discharge medication errors.

On an organisational level, it is advisable for the discharge initiatives and policies available to support effective and safe discharge for people living with dementia.

The findings of the systematic review synthesis reveal the experience of people living with dementia and their carers during the hospital discharge process in the pre-pandemic context. It is evident that people living with dementia and their carers are often excluded from the discharge planning process and have negative experiences of the discharge due to a range of different factors. One of the objectives of this research was to conduct a qualitative systematic review to identify and synthesise available evidence, regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. This has been achieved within this chapter. However, as identified above, there was no literature identified that explored the impact of the pandemic, and the gap in the literature regarding research into the nature of wellbeing during the discharge process for people living with dementia and their carers was identified. In the next chapter, I will identify the policy available in relation to the hospital discharge process, and the policy that was issued during the COVID 19 pandemic relating to the hospital discharge process in England.

Chapter 3. Exploration of policy context

3.1 Introductory paragraph

The hospital discharge process is governed by the policy issued to guide clinicians and NHS Trusts in their practice. This research study is based in England and therefore, the guidance available in the English context will be explored. It is important to understand the policy in existence during the research study to identify the impact of such policy on the discharge process and the practice of health and social care professionals. Understanding the policy available also enables a greater understanding of carer, and health and social care professional, experiences. This chapter will first explore the different definitions available of the hospital discharge process. It will then outline the interpretivist approach to policy review and explore the policy documentation available related to the hospital discharge process for people living with dementia and their carers. Following this, the chapter will contrast the content of the policy issued during the COVID 19 pandemic, to previously established policy, to explore the differences in approach during this period. This will help illuminate the context of the empirical data.

3.2 Definitions of the discharge process

A brief look at the different definitions of hospital discharge reveals contradictory perspectives and approaches to the process of leaving the hospital. In the USA, the John Hopkins Medicine organisation defines the discharge process in terms of being instructed as to when you can leave the hospital and the end of the need for inpatient care:

> *'When you leave a hospital after treatment, you go through a process called hospital discharge. A hospital will discharge you when you no longer need to receive inpatient care and can go home. Or a hospital will discharge you to send you to another type of facility.'*
>
> *(John Hopkins Medicine, 2022)*

The NHS definition is much broader with more emphasis on patient and carer involvement in the discharge process.

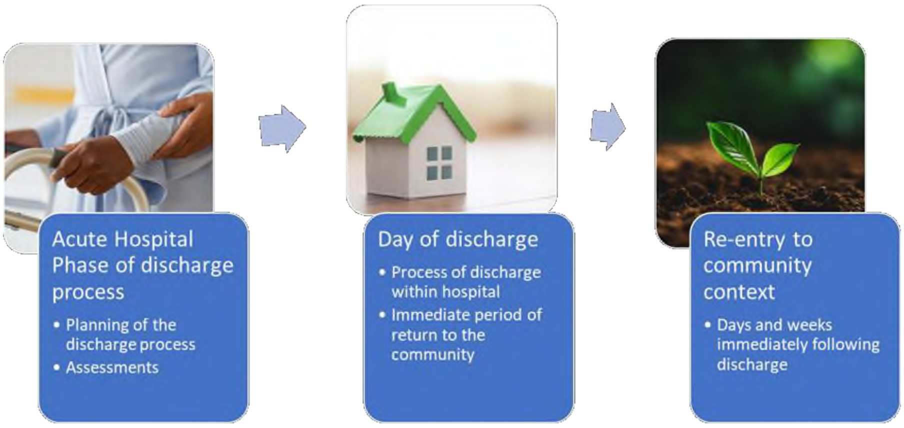
> ‘*Once you're admitted to hospital, your treatment plan, including details for discharge or transfer, will be developed, and discussed with you. A discharge assessment will determine whether you need more care after you leave hospital. You should be fully involved in the assessment process. With your permission, family or carers will also be kept informed and given the opportunity to contribute.’*
>
> *(NHS England, 2022a)*

It is worth noting that the span and scope of the definition of hospital discharge differs in these two different characterisations. The American version identifies the discharge as a discreet period at the end of the hospital stay (John Hopkins Medicine, 2022). The NHS definition is much wider in scope and time. It places the person being discharged and their family at the centre of the process and suggests that the discharge planning process takes place over a longer period (NHS England, 2022a). It is worth noting that within this research project the span of the discharge process is defined even more broadly than either of these definitions. It is contended that the discharge process should be defined as including the immediate period after the person leaves the hospital period. This is a period of readjustment and of re-entering the community, potentially to a different setting due to the changes in condition caused by the period before the hospital stay, or the hospital admission itself.

For a person living with dementia, the chance of readmission to the hospital within 90 days of the discharge is very high. Exact re-admission figures are unclear. A systematic review published pre-pandemic suggested an international re-admission figure anywhere between 7 and 35% for people living with dementia (Ma *et al.*, 2019). A UK report by Dementia Action Alliance suggested a 25% readmission rate in the UK (Dementia Action Alliance, 2013). Whichever of these figures is accurate is somewhat irrelevant, as even the lowest figure suggests that often the discharge process is not successful for people living with dementia and should include this immediate period after physically leaving the hospital, as this represents a litmus period for whether the discharge process has been effective. It is important to note that some readmission will occur for legitimate reasons.

A recent quantitative study of data from a large London hospital suggested that within two years of being diagnosed, 75% of people living with dementia will be admitted to hospital (Sommerlad *et al.*, 2019). Therefore, it is highly likely that most people living with dementia will experience the process of hospital discharge. The discharge process for people living with dementia is significantly more complex than the average hospital discharge for people who do not live with dementia, or have entered the hospital for treatment (Mockford, 2015). People with dementia are more likely to need social care or residential care, may no longer have capacity, and may have significant co-morbidities on leaving the hospital (National Institute for Health and Care Excellence, 2022). Therefore, the hospital discharge process must be appropriate and supportive of this patient group.

The discharge process can be characterised as having three distinct stages as demonstrated in Figure 4 which diagrammatically depicts the discharge process.



Creative Comms Images 2022

Figure 4. Diagram of stages of the discharge process

Understanding and constructing the discharge process in this way allows the full experience of the discharge process, as understood by the person living with dementia and their family, to be analysed. In alliance with the social constructionist ontology of this research project, the discharge process will have different fundamental meanings for different stakeholders involved, but illustrating the discharge process in the manner provided allows for the most comprehensive overview in relation to this project.

Before discussing the policy specific to the discharge process for people living with dementia and their carers it is important to explore the concept of the 'delayed discharge' and the role this plays in how people living with dementia are often conceptualised in the hospital sphere.

3.3 Delayed discharge

There is an acceptance in practice and policy literature that people living with dementia often function as 'bed blockers' within acute general hospitals. This is a value laden term (Leighton, 2002), which suggests that people living with dementia are in hospital when they should not be and are preventing other members of the population accessing services (Manzano-Santaella, 2003). The term 'bed-blocker' is largely unused in recent policy and practice literature due to the pejorative nature of the term. The Department of Health began using the phrase 'delayed transfer' in 2002 as an answer to the stigma surrounding the term.

The 'delayed transfer' has been identified in the literature as problematic. Both Digby, Lee and Williams (2018) and Manzano-Santaella (2003) identify that this is because the UK Government selected reduction in length of stay as an efficiency tool. Bed occupancy targets entail that hospital culture desires a rapid movement of patients through the system to reduce costs. People living with dementia move more slowly through the system and, as such, are considered a hinderance to efficiency and given a diminished and pejorative status within the hospital. Kumar, Shinge and Parameshwar (2010) identified that the average length of stay considered to be 'bed-blocking' was 31 days, but this is a subjective description.

The NHS has clear definitions regarding the nature of a ‘delayed discharge’. The Hospital Discharge and Community Support Guidance from the Department of Health and Social Care (2022e) has very narrow criteria for remaining in hospital. The criteria are medically orientated and have very limited scope. They include: ‘being 24 hours away from invasive surgery or requiring ITU or HDU care? requiring oxygen therapy? requiring intravenous fluids? NEWS2 greater than 3? (clinical judgement required in persons with Atrial Fibrillation and/or chronic respiratory disease) diminished level of consciousness where recovery is realistic? acute functional impairment in excess of home/community care provision? last hours of life? requiring intravenous medication > b.d. (including analgesia)? Having undergone lower limb surgery within 48 hours? Having undergone thorax-abdominal or pelvic surgery with 72 hours? within 24 hours of an invasive procedure? (with attendant risk of acute life- threatening deterioration)’ (Department of Health and Social Care, 2022e, p. 41). Such a limited criterion for remaining in hospital entails that many patients can be routinely identified as ‘bed- blockers.’

Manzano-Santaella (2003) identifies that within practice literature there are two main reasons normatively given for the bed blocking phenomenon. A failure in the discharge planning process, this approach generally blames social services for failing to offer timely resource, or a shortage of care within the community. This interpretation is evident in a significant amount of the literature in this area. Gaughan, Gravelle and Siciliani (2015) identify that there is a significant relationship between limited care home placements and the number of delayed discharges. Similarly, Holmås, Islam, and Kjerstad (2013) identify that there is a relationship between the expansion of social service provision and a reduction in delayed discharge. However, other evidence disputes these findings.

Carter *et al* (2004), argues that there are many factors involved in why an individual’s discharge may be delayed across both the hospital and community setting. Glasby, Littlechild and Pryce (2004) acknowledged that delays are often caused by waiting for interprofessional meetings or specialist input. These findings are at odds with the reasons usually conceptualised as to why a patient may ‘bed block’. Carter and Wade (2004) argued that the concept of a ‘delayed discharge’ itself is flawed, as it is subjectively decided by individual physicians. Vetter (2003) argues that there is no way to define a delayed discharge, as there is no way to distinguish what is an inappropriate delay. Further to this, Clark and Rosen (2001) argue that the concept of the delayed discharge is a mistaken one. Instead, they argue that the idea that hospital stays should be short and efficient is flawed, and instead that some patients should have longer stays as they can be beneficial. However, as the concept of delayed discharge is embedded in policy literature, it is difficult for people living with dementia to avoid the stigma of the concept of delayed discharge.

3.4 Interpretivist approach to policy review

A review of the health and social care policy documentation is crucial to understanding the context in which the hospital discharge process is situated. I returned to policy documentation at different stages of the PhD project. These stages included: during the initial development stages of the research project; following the data collection phase; and during the analysis process. Exploring theorists such as Bowen (2009), Bletsas (2012), Silverman (2015) and Fischer *et al.* (2015), helped with the identification of the type of policy analysis relevant to understanding the data collected.

It was identified that an interpretative approach would enable the exploration and explanation of the key policies underpinning the discharge process, in a manner complimentary to the ontology of the research project (Browne *et al.*, 2018). This approach contrasts with other policy analysis approaches which can have a positivist focus, and examine areas such as cost-benefit analysis, implementation approaches or how and why a policy is developed and whether it is objectively ‘successful’ (Browne *et al.*, 2018). The method of document review outlined by Bowen (2009), which adopts an iterative process combining elements of both thematic and content analysis has been implemented in this chapter. A practical, firmly qualitative approach to policy document review, outlined in detail by Cardno (2019) has also been employed. This approach recommends reviewing a document through three key areas: policy context, policy text and policy consequences.

The definition of policy context includes exploring the political climate and socio-economic environment leading to the formation of the policy (Cardno, 2019). Analysis of the policy text comprises of: investigating what is stated within the policy; inferences about theories and values that may be influencing the actual text; language use within the document; the overall structure of the document; and identifying what is not stated transparently within the text but may be implied or even omitted within the document (Silverman, 2015). Policy consequences include how the individuals implementing the policy understand it, unexpected outcomes, and the potential challenges of implementation which the researcher can identify (Bletsas, 2012). This is a critical and evaluative approach to policy analysis which allows the policy to be interrogated for its underpinning influences and purposes. Some of these areas may not be explicitly stated or even obvious on first reading of the documentation. This approach has allowed for the consideration of the three domains explicitly during the analysis of the policy documentation and enabled the contrast of the documentation produced before and during the pandemic. This revealed the 'gaps' evident within the documentation, and the explicit and implicit focus of pandemic policy, in comparison to earlier policy publications in this subject area. The next section of this chapter will outline how using this interpretivist approach helped with understanding the policy produced, before and during the pandemic, in a manner that contextualised the data collected.

3.5 The discharge process

3.5.1 Context

This section will begin by outlining the context in which hospital discharge policy has developed, before moving on to consider the text of the policy that has been issued in the last 10 years, and finally the consequence of the policy guidance. The past 20 years have seen radical metamorphosis of health and social care in England. Successive governments have moved away from the founding principles of the NHS towards a neo-liberal approach which places emphasis on competition, marketisation and individual responsibility (Delamothe, 2008; Department of Health, 2012; Allen *et al.*, 2017). These changes have been met with criticism and the argument that the new emphasis on choice is really a smoke screen for a move towards greater responsibility for the individual (Department of Health, 2012; Den, Exter and Guy, 2014). The discharge process has not been immune to these changes and has altered to reflect the realities of leaving the hospital in the twenty-first century. The process has transformed to meet the reality of a growing population of older adults, leaving the hospital with a dementia diagnosis, and the many health and social considerations which must be addressed during this process.

Several different guidance documents (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; National Institute for Health and Care Excellence, 2018) have been issued in response to this changing context to ensure that the discharge process is appropriate for this patient/carer group in the twenty- first century. These publications are listed in figure 5 alongside policy issued during the COVID 19 pandemic. Publications (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; National Institute for Health and Care Excellence, 2018) outline expectations about how the discharge process should operate for adults with social care needs. This includes people living with dementia. It is noted that this guidance is not specifically for the population living with dementia. It could be argued that the generality of the National Institute for Health and Care Excellence (NICE) guidance, in relation to the discharge process, could benefit from more specificity in relation to dementia conditions. This is due to the unique implications of the condition, and the reality that nearly 33% of individuals being admitted to hospital will have a dementia diagnosis in 2022 and 2023 (Office for Health Improvement and Disparities, 2022).

People living with dementia are at high risk of adverse events during both the hospital admission period and during the discharge process, due to the impact of the condition on cognition (Fog, Griffiths, Meredith, and Bridges, 2018). Kable *et al* (2019) identified the vulnerability of people living with dementia to medication errors during this period. Further to this, Neziraj *et al* (2021) identified that individuals in dementia care units had a higher vulnerability to pressure ulcers, malnutrition, poor oral health, and falls. This longitudinal study highlights the unique implications of this condition for this patient group and their specific vulnerabilities due to the cognition impact of dementia.

People living with dementia have more complex needs than patients who do not live with dementia due to the impact of the condition on their short- and long-term memory, the impact of the progressive condition on mobility, and ability to attain adequate nutrition; the potential to experience hallucinations and problems with language and communication (Alzheimer's Society, 2023). The impacts described above are not generally present in patients without cognitive impairment, even if they require social care input or would be described as frail. Therefore, specific guidance that considers the impact of these complex presentations would be beneficial to aid people living with dementia in a more targeted and person-centred way.

Why the decision to issue hospital discharge guidance for such a broad population, unaccompanied by a smaller subsection of more nuanced guidance directed at people living with dementia, was taken is unclear. Recent research has explored the potential impact of a patient and public involvement group on the development of policy relating to hospital guidance (Malfait *et al.*, 2018). The involvement of individuals with lived experience would offer a potential route to developing a more specialised subsection of guidance. The need for specific guidance for individuals living with dementia and their carers will be justified by the increasing number of people living with the condition, and its status as the number one cause of death within the UK (Office of National Statistics, 2022). This number will significantly increase over the next ten years based on current predictions (Alzheimer's Research UK, 2018). It should be noted that the 2018 guidance- 'Dementia: assessment, management and support for people living with dementia and their carers' (National Institute for Health and Care Excellence, 2018) which is specific to people living with dementia, simply refers to the 2015 and 2016- 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs' National Institute for Health and Care Excellence guidance, without adding anything new in relation to the discharge process specifically.

Five quality statements were issued by the National Institute for Health and Care Excellence (2016) that should be adhered to during the discharge process of adults living with dementia with complex needs from the acute hospital setting. They are outlined in Extract 1. This extract has been selected as it outlines the central tenets of the actions that should be taken during the discharge process. The discharge process, as defined by the guidance issued in 2015, chooses to characterize the discharge process beyond the physical leaving of the hospital space, and into the initial period settling back into the community. This is in accordance with the definition of this research project (National Institute for Health and Care Excellence, 2015). The key policy statements of the guidance aimed at older adults, living with dementia with complex needs, being discharged from an acute hospital (National Institute for Health and Care Excellence, 2016) are outlined in Extract 2. Extract 2 has been included as it outlines some of the central responsibilities of the hospital discharge team to ensure that bed pressures are not the primary driver of discharge, and that carers and family are involved in the discharge process and safeguarded. These tenets are important because there is independent evidence revealing the negative impact of discharging due to bed pressures, or decision making in crisis (Friebel *et al*, 2019). The importance of relative and carer involvement in discharge planning is established within wider literature and government guidance (Hesselink, 2014, NHS England, 2023).

Extract 1 Transition between inpatient hospital settings and community or care home settings for adults with social care needs**.** Quality statements. (National Institute for Health and Care Excellence, 2016)

Statement 1: Adults with social care needs who are admitted to hospital have existing care plans shared with the admitting team.

Statement 2: Older people with complex needs have a comprehensive geriatric assessment started on admission to hospital.

Statement 3: Adults with social care needs who are in hospital have a named discharge coordinator.

Statement 4: Adults with social care needs are given a copy of their agreed discharge plan before leaving hospital.

Statement 5: Adults with social care needs have family or carers involved in discharge planning if they are providing support after discharge.

(National Institute for Health and Care Excellence, 2016)

Extract 2 Transition between inpatient hospital settings and community or care home settings for adults with social care needs (National Institute for Health and Care Excellence, 2015)

1.5.11 Ensure that people do not have to make decisions about long-term residential or nursing care while they are in crisis.

1.5.12 Ensure that any pressure to make beds available does not result in unplanned and uncoordinated hospital discharges.

1.5.15 The discharge coordinator should ensure that the discharge plan takes account of the person's social and emotional wellbeing, as well as the practicalities of daily living.

1.5.29 The hospital- and community-based multidisciplinary teams should recognise the value of carers and families as an important source of knowledge about the person's life and needs.

1.5.31 If the discharge plan involves support from family or carers, the hospital-based multidisciplinary team should take account of their: willingness and ability to provide support; circumstances, needs and aspirations; relationship with the person; need for respite.

1.5.32 A member of the hospital-based multidisciplinary team should discuss the practical and emotional aspects of providing care with potential carers.

(National Institute for Health and Care Excellence, 2015)

The text of the 2016 quality standards (National Institute for Health and Care Excellence, 2016) reveals what is valued, for adults living with dementia, during the acute hospital discharge process. The emphasis on assessment, a discharge co-ordinator and an agreed discharge plan reveals that extensive planning is highly valued. The involvement of the family or carers of adults with social needs within the fifth statement, indicates that there is an acknowledgement of the importance of genuine and meaningful involvement from carers and family within the discharge planning process. The detail of a comprehensive geriatric assessment also reveals that the standard is looking to move the discharge process beyond a focus on simply medical concerns.

No external review of the implementation of these quality standards has been undertaken. It is difficult to assess how these standards have been adopted and whether they are adhered to in practice. Quality standards such as these are aimed at improving care standards, but as stated within the text of the document, ‘expected levels of achievement for quality measures are not specified’ (National Institute for Health and Care Excellence, 2016, p. 22). Therefore, it is challenging to assess whether they have been successfully implemented.

The 2015 guidance is appreciative of the role and expertise of the carer within the discharge process and the requirement for their needs, including the requirement for adequate respite, to be considered, and for appropriate support and training to be offered. This is detailed in section 1.5.29 and 1.5.32 (National Institute for Health and Care Excellence, 2015). Furthermore, the importance of not choosing long term residential accommodation when in crisis is emphasised in section 1.5.11 (National Institute for Health and Care Excellence, 2015). There is an emphasis on the requirement for a discharge co-ordinator, who can provide a point of contact and be the link between the community and the hospital, and this is emphasised in section 1.5.1 (National Institute for Health and Care Excellence, 2015). There is also the clear statement not to put the pressure for hospital beds above the need for a well-planned and co-ordinated discharge in section 1.5.12 (National Institute for Health and Care Excellence, 2015). It is important to note that these aspects of the guidance highlight the policy’s aim to support the needs of the patient and the carer during the discharge process. It is important to identify the content of the National Institute for Health and Care Excellence guidance (2015) in contrast to the policy guidance issued during the pandemic.

One of the most telling aspects of the guidance is the emphasis placed on ensuring wellbeing during the discharge process in section 1.5.15 (National Institute for Health and Care Excellence, 2015**.** This places an emphasis on the discharge co-ordinator to consider the wellbeing of the person living with dementia. The recommendations also ask for, ’a better experience of transitions between hospital and home’ (National Institute for Health and Care Excellence, 2015, p. 21), and place a clear emphasis on carer wellbeing alongside patient wellbeing. It is argued in the implementation section, in relation to person centred care that, ‘carers specialist understanding of the person living with dementia is realised and that carers are helped to protect their own wellbeing’

(National Institute for Health and Care Excellence, 2015, p. 19). Further to this, there is a requirement to promote wellbeing placed on health and social care professionals, (National Institute for Health and Care Excellence, 2015).

The guidance is very transparent about the requirement for wellbeing, beyond physical needs, to be addressed within the discharge process. It is unfortunate that how to support wellbeing during the discharge process is not outlined. This causes the term wellbeing to remain opaque for both carers and people living with dementia. In the previous section, the potential of patient and public involvement to delineate specific guidance in relation wellbeing was identified (Malfait *et al.*, 2018). This offers a potential route to more detailed guidance regarding how to support wellbeing during the discharge process and could be added as an addendum to the more general guideline.

If the omission of detail and clarity, in relation to how to support wellbeing in practical terms is deliberate, then the motives for this must be considered. Wellbeing is defined within the Care Act (2014) (see definition in Extract 3) but in very broad terms only, with an emphasis on individual responsibility centralised. It is not defined as a term specifically for individuals living with dementia, or their carers, nor is it defined in specific contexts. In the next section of this chapter, I will outline some of the consequences of the impact of policy documentation available before the pandemic, and progress to discussing the policy issued during the COVID 19 pandemic.

Extract 3 Wellbeing definition from The Care Act (2014)

Wellbeing as defined in The Care Act (2014)

Well-being”, in relation to an individual, means that individual’s well-being so far as relating to any of the following—

(a) personal dignity (including treatment of the individual with respect);

(b) physical and mental health and emotional well-being.

(c) protection from abuse and neglect.

(d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided).

(e) participation in work, education, training or recreation.

(f) social and economic well-being.

(g) domestic, family and personal relationships.

(h) suitability of living accommodation.

(i) the individual’s contribution to society.

(Department of Health, 2014a)

3.5.2 Consequence

The requirements of the 2015 guidance reflect the necessity for adequate organisation within the discharge procedure, and a process which values the involvement of carers. However, a significant criticism of the guidance is that wording and meaning is vague. An example of this is, ‘health and social care organisations should agree clear discharge planning protocols’ (National Institute for Health and Care Excellence, 2015, p. 11). There is no clarity concerning what those protocols should include. There is also very vague advice related to communicating with and supporting carers in section 1.5.7. (National Institute for Health and Care Excellence, 2015, p. 11). The advice provided suggests that support and training could include a face-to-face meeting with practical training, or only the provision of a leaflet.

These forms of support are very different in character. A consequence of the flexibility to provide a face-to-face meeting, or a leaflet, will ensure significant diversity in provision across the UK, with different hospital trusts free to make different decisions. It could be argued that the support carers will experience will be significantly different if offered a face-to-face meeting, versus a leaflet. The lack of detail included in the 2015 guidance (National Institute for Health and Care Excellence, 2015) could be linked to a desire not to commit to any specific actions, but instead allow individual health and social care settings to interpret guidance however they choose. The consequence of this could be that the lack of guidance available may lead to confusion in practice, and possibly an omittance of wellbeing considerations during the discharge process, due to the absence of concrete and detailed recommendations for specific actions.

If we turn our attention to the 2016 quality standards (National Institute for Health and Care Excellence, 2016), it is important to note that each standard is defined in a multitude of ways within the guidance. Each standard indicates separately what the standard will mean to commissioners, health and social care practitioners and people living with dementia, or with other conditions which can render patients, and their carers vulnerable. A consequence of this approach is that it indicates a social constructionist understanding of what the discharge process is and how it operates.

This acknowledgement that the quality standards have different meanings for different individuals involved in the discharge process, reveals the subjectivity of discharge, and the importance of taking an approach to assessment that allows for diverse opinions and perspectives. It indicates that the only meaningful review would be one that was qualitative, and approached the topic of discharge from an ontology that acknowledged the multitude of perspectives involved in leaving the hospital. In accordance with this, during this research project the quality standards will be considered and whether the quality standards are being upheld in the opinion of the researcher will be addressed in the discussion section of this thesis.

The 2015 and 2016 NICE guidance remains ambiguous partly because of the wide population it is aimed at. The guidance is primarily for adults requiring social care, not specifically people living with dementia. There is some information included referring to homelessness and the requirements of individuals who have experienced a stroke. Generally, people living with dementia experience a capacity assessment close to discharge (Emmett *et al.*, 2013), and this has been flagged in previous research as an area that requires further attention during the discharge process. However, there is no in-depth consideration of this issue which leaves the task of assessing capacity particularly vague during the discharge process. As previously argued, the guidance would benefit from a specialised subsection that addresses the needs of individuals living with dementia and their carers. It has been identified that people living with dementia and their carers have very specific requirements that should be considered (Emmett *et al.*, 2013), and this is not currently possible because of the guidance available. The input of public advisors in the compiling and drafting of subsequent guidance, may offer a potential approach to tackle this lack of specificity.

During the formulation of this research project, the guidance available was reviewed as the primary policy documentation regarding how the discharge process should function to support carer and patient wellbeing (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2018). The limitations of the guidance were noted but the usefulness of the guidance, as a place to consider and compare the practice observed, and the experiences of carers and professionals was appreciated. However, during the first year of the project new guidance was issued which was to have a significant impact on the discharge process. The next section of this chapter will explore and review the discharge policy formulated by the UK Government at the beginning of the pandemic and compare it to previous guidelines.

3.6 COVID 19 policy and the discharge process

The infographic in Figure 5 details the policy documentation released since 2015 relevant to the discharge process and people living with dementia.

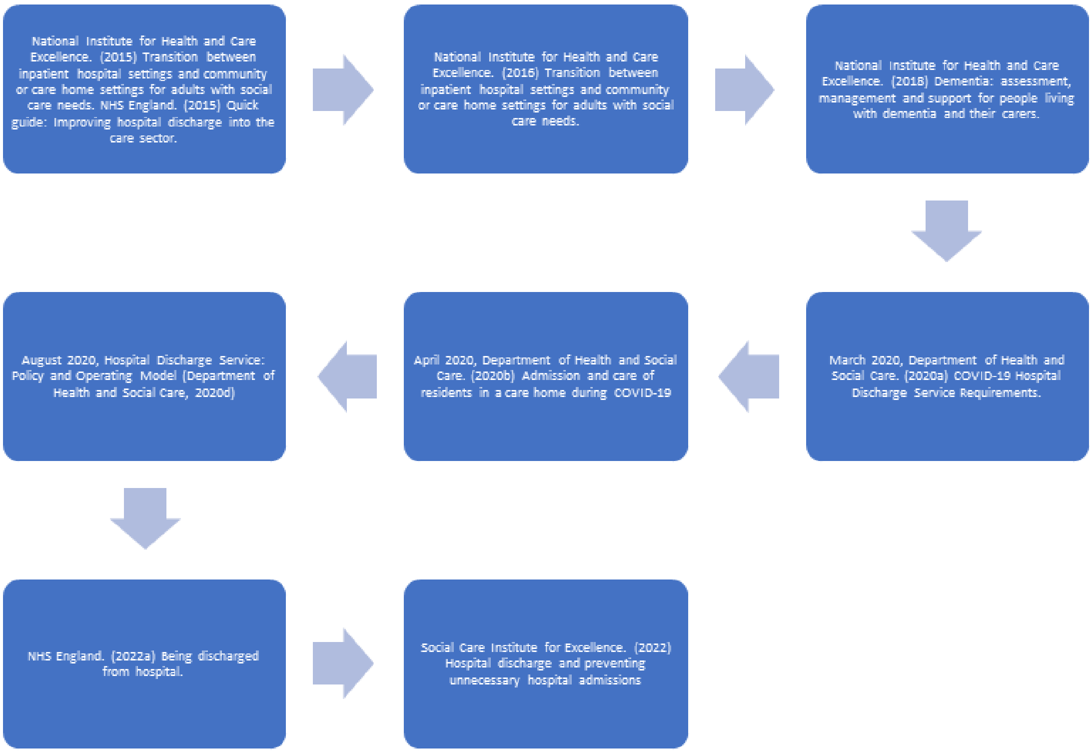


Figure 5: Infographic of UK policy documentation related to the discharge process since 2015.

3.6.1 Context

In March 2020, new policy and guidance was issued in response to the COVID 19 pandemic which was to have a significant effect on the discharge process and people living with dementia and their carers. In response to the threat of COVID 19, in March 2020 the UK Government issued guidance which aimed to discharge all patients who were medically fit as soon as possible (Department of Health and Social Care, 2020a). Some of the key aspects of the first pandemic policy guidance related to the discharge process and issued in March 2020 are presented in Extract 4. Extract 4 has been included as it succinctly outlines the expectations of the UK government regarding the rapid discharge of patients during the onset of the COVID 19 pandemic.

3.6.2 Text

Extract 4 March 2020 Section 1.3 COVID-19 Hospital Discharge Service Requirements (Department of Health and Social Care, 2020a).

- Acute and community hospitals must discharge all patients as soon as they are clinically safe to do so. Transfer from the ward should happen within one hour of that decision being made to a designated discharge area. Discharge from hospital should happen as soon after that as possible, normally within 2 hours.

- For 95% of patients leaving hospital this will mean that (where it is needed), the assessment and organising of ongoing care will take place when they are in their own home.

- For patients whose needs are too great to return to their own home (about 5% of patients admitted to hospital) a suitable rehabilitation bed or care home will be arranged. During the COVID-19 pandemic, patients will not be able to wait in hospital until their first choice of care home has a vacancy. This will mean a short spell in an alternative care home and the care coordinators will follow up to ensure patients are able to move as soon as possible to their long-term care home.

- During the COVID-19 pandemic, all of the above support will be paid for by the NHS, to ensure patients move on from their acute hospital stay as quickly as possible'.

3 Central Questions

- Why not home?
- What needs to be different to make this possible at home?
- Why not today?

(Department of Health and Social Care, 2020a)

Section 1.3 of the guidance issued in March 2020 (Department of Health and Social Care, 2020a), argued for rapid discharge once it was clinically safe to do so, and the development of specific discharge areas (Department of Health and Social Care, 2020a). This guidance, designed to 'free up' beds, revamped the discharge process from one where assessments took place on the ward to a model where patients were moved to the discharge lounge, and assessed in a community bed, or within the home, after leaving hospital. Funding was made available to facilitate this new, faster discharge process and this was outlined in section 2.6 of the new guidance. It was also stated that individuals should not wait in hospital but be discharged to interim beds if necessary to facilitate their removal from the hospital. There is very little mention of testing for COVID 19 before discharge, in the guidance issued in March 2020, except to state that test results should accompany patients on discharge 'where applicable' (Department of Health and Social Care, 2020a, p. 8). The 'discharge to assess' model introduced within the guidance to speed up the discharge process, asked clinicians to refer to three key questions every day outlined in Extract 4.

3.6.3 Consequence

It is evident that the March 2020 guidance places the requirement to empty beds within the hospital as the central concern, above the welfare of patients, particularly those with needs requiring residential care post discharge. Rehabilitation beds or alternative care home placements were prioritised to ensure a quicker discharge. Moving people living with dementia multiple times has long been identified as problematic (Moyle *et al*., 2008) and consequently, this guidance was clearly detrimental to people living with a dementia.

The focus of the policy on ensuring that patients left the hospital space and explicit mention of ‘positive risk taking’ (Department of Health and Social Care, 2020a, p. 28) ensured that the discharge atmosphere was not focused on person centred care during this period but rather the requirement to discharge speedily.

The limited guidance regarding COVID 19 testing at discharge within the March 2020 guidance (Department of Health and Social Care, 2020a), led to hospital discharges taking place without any COVID 19 testing. A consequence of the ‘discharge lounge model,’ was that patients who were being discharged moved from one ward setting to a communal discharge lounge setting, without any testing for COVID 19 occurring. There was no consideration of testing before entry to a care home, and no discussion around isolation in the guidance issued in March 2020. The extra movement of people living with dementia into a discharge lounge, and the impact this would have on their wellbeing was also not considered.

3.7 Further policy related to the hospital discharge process issued during 2020 in response to the pandemic.

Extract 5 August 2020 Hospital Discharge Service (Department of Health and Social Care, 2020d)

‘Ensure COVID-19 testing of all people being discharged from hospital to a care home, in advance of a timely discharge (as set out in the Coronavirus: adult social care action plan). Where a test result is still awaited, the person will be discharged if the care home states that it is able to safely isolate the patient as outlined in Admission and Care of Residents in a Care Home guidance’.

‘On decision of discharge, the person and their family or carer, and any formal supported housing workers should be informed.’

(Department of Health and Social Care, 2020d)

The UK government continued issuing guidance, in relation to the hospital discharge process, throughout the pandemic including in August 2020 (Department of Health and Social Care, 2020d) (Extract 5). Guidance was issued 04 April 2020 (Department of

Health and Social Care, 2020b) which began to identify the requirement for testing prior to a discharge from the hospital setting, into the care home setting. This document had been withdrawn by the time of drafting this thesis, and the document accessible to the public had been updated many times since first issued to reflect the changes in isolation periods over the latter period of the pandemic. The final update was added in March 2022. During the editing process of this thesis, it became apparent that it has since been withdrawn as of 1 April 2022. This document (Department of Health and Social Care, 2020b) referenced the wellbeing definition from The Care Act (Department of Health, 2014a) as being an important consideration during the discharge process, but it is difficult to identify when this was added as a clause, due to the numerous updates to the guidance. The documentation issued on April 15, 2020 (Department of Health and Social Care, 2020b), mentioned at section 1.3, that testing will shortly be instated before discharging people living with dementia from the hospital to a care home, but explicit plans are not detailed at that point. There is also no explicit discussion of wellbeing in this document at this point.

The guidance issued in August 2020 (Department of Health and Social Care, 2020d), is in marked contrast to the March 2020 documentation (Department of Health and Social Care, 2020a). Testing for COVID 19 and isolation requirements, if being discharged to a care home, are explicitly outlined, and included in Extract 5 (Department of Health and Social Care, 2020d, p. 18). This has been included as an extract to explicitly highlight when testing and isolation was established within policy guidance, and the beginning of the change of direction from rapid discharge to more measured actions with a wellbeing focus. Section 2.10 details the ongoing financial support available to promote quicker hospital discharge during the pandemic period. In the next section, the policy issued during the pandemic will be compared with the guidance issued in the post pandemic period.

3.8 Comparison of March and August 2020 guidance with 2015 and 2016 policy documentation

The tone and format of the guidance issued in March 2020 (Department of Health and Social Care, 2020a) and August 2020

(Department of Health and Social Care, 2020d) differs markedly from guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016). The emphasis of the 2016 and 2015 guidance on wellbeing, for both patients and carers, is missing in the guidance issued during the pandemic in its early stages. The stated goal of the 2015 guidance in section 1.5.12 (National Institute for Health and Care Excellence, 2015) to ensure that the need for available hospital beds is not put above the wellbeing of the patient, and that there is a well-planned, well-co-ordinated hospital discharge, is entirely contradicted by the guidance issued in March 2020 and August 2020 (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020d). Pandemic policy prioritised the requirement to discharge quickly and liberate hospital beds above all other needs including wellbeing. The subjective positioning of the guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016) which acknowledged multiple perspectives, including those of carers, patients, and other stakeholders, is not evident in the guidance issued in March 2020 and August 2020 (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020d). The tone and approach of the guidance follows the medical paradigm, which views the discharge process as a specifically medical process aimed at removing a ‘well’ patient from the acute environment to a community setting.

There is mention in the guidance issued in August 2020 (Department of Health and Social Care, 2020d) that relatives and carers should be merely informed when their relative is going to leave hospital. This could not be more different from guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016), which emphasised the importance of joint and shared decision making between carers, people living with dementia and health and social care professionals. Statement 5 of the 2016 guidance (National Institute for Health and Care Excellence, 2016) provided clarity regarding the importance of this joint working and decision making, at all times, during the discharge planning process. This small example highlights the significant differences in policy issued pre-pandemic, and the policy drafted during the pandemic. The priorities of pandemic context guidance are evident and do not include wellbeing as defined in The Care Act (2014). The consequences of these priorities were evident in the early months of the pandemic. In the final section of this chapter, we will consider the policy that has been released in the aftermath of the pandemic, and how wellbeing has been positioned more recently in policy related to the discharge process.

3.9 Review of guidance released in the aftermath of the pandemic impact.

Extract 6

The Social Care Institute for Excellence Hospital discharge and preventing unnecessary hospital admissions (COVID-19) (Social Care Institute for Excellence, 2022)

'Rapid hospital discharge and avoidance, especially in the early months of the pandemic resulted in deaths, trauma, limits to people's freedom and choices, and many people not getting support that is right for them'.

'What can be done quickly and safely to improve people's health and wellbeing?'

(Social Care Institute for Excellence, 2022)

The Social Care Institute for Excellence (2022) produced a report aimed at commissioners, and updated in January 2022, which acknowledged that the emphasis on quick discharge at the beginning of the pandemic led to deaths, limits on freedom and choice, and many not receiving the correct support (Social Care Institute for Excellence, 2022). Extract 6 has been included because it emphasises how the new guidance for health care commissioners issued in 2022, shares more common ground with previous guidance, than pandemic policy (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016). Wellbeing is once again highlighted as requiring specific consideration (Social Care Institute for Excellence, 2022). The acknowledgment of the mistakes of the earlier guidance outlined in Extract 1 is evident. However, the discharge to assess model is still strongly favoured, and the 'core principles' of a good discharge process continue to adhere to the neo-liberal agenda, with leadership, choice, agile and confident leadership, co-production, communication and integration and collaboration (Social Care Institute for Excellence, 2022) being promoted. There is also an emphasis on the voluntary sector which fits the neo-liberal model (Social Care Institute for Excellence, 2022).

The ‘where best next?’ campaign which favours a discharge to assess model to speed up the discharge process is still centralised in current guidance for commissioners (Newton Europe, 2019). However, it was produced before the pandemic period, and its content appears at odds with the most recent report which acknowledges that rapid hospital discharge is problematic. It is also at odds with the recent government decisions to discontinue discharge to assess funding from March 2022 (Social Care Institute for Excellence, 2022). The NHS quick guides to hospital discharge, which are signposted on the guide for commissioners updated in January 2022, are pre-pandemic documents dating from 2015 (NHS England, 2015). These guides identify potential local solutions from individual health economies which seems to support the fragmentation of services into small individual local provisions (NHS England, 2015). It appears that the guidance available concerning the discharge process, and particularly the hospital discharge process for people living with dementia and their carers, requires further attention from policy makers, and substantial re-consideration in the aftermath of the pandemic. New guidance that incorporates an awareness of the drawbacks of a rapid discharge process for people living with dementia and acknowledges that with the discontinuance of funding in March 2022, the discharge to assess model requires re-consideration. It is my contention that the guidance currently available is not fit for purpose.

At this point it must be acknowledged that during the drafting of this thesis and weeks after the above paragraphs were written, on the 27th of April 2022, the High court in England found that the Government’s guidance issued between 17th March 2020 and 4th April 2020 under the then Secretary of State for Health and Social Care was unlawful (Holt, 2022). The guidance was described as a failure of policy (Holt, 2022) that omitted to protect vulnerable older people being admitted to care homes from hospital.

The specific policy documentation discussed within this thesis (Department of Health and Social Care, 2020a), was identified as failing in its duty of care towards older, vulnerable adults in relation to asymptomatic transmission, and the testing of patients being discharged from hospital. The public inquest into this failure is scheduled for some time in 2023 which lies outside of the timeframe of this PhD. It is in the shadow of this policy, which has been identified as unlawful and a failure, that my PhD project was implemented. Many of the professional participants involved in this study were making clinical decisions in the light of the 2020 policy guidance detailed (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020b), and carer participants were often discussing their experiences in the period in which this guidance was in place. Therefore, it is important to situate the findings presented within this policy context. These contextual policy elements are important to remember when reading the findings of this research project regarding the impact of COVID 19 on the discharge process, and how this impacted on the wellbeing of carers and people living with dementia.

This chapter has provided an analysis of the policy documentation, for people living with dementia and their carers, in relation to the hospital discharge process and wellbeing in both the pre-pandemic and pandemic era. This provides the context of the study and reveals how the guidance was flawed in its ability to promote wellbeing during the discharge process before the pandemic, and how policy issued at the beginning of the pandemic undermined potential efforts to ensure wellbeing within the pandemic era. This chapter has also argued that the policy and guidance published in 2022 is not fit for purpose and needs significant attention to engender a discharge process which can enable the wellbeing of people living with dementia and their carers. The next chapter will progress from the literature and policy context to outline decisions made in relation to the ontology and methodology of this research project. It will trace the original methods identified in 2019, and how these methods changed in response to the pandemic, and the restrictions experienced by all researchers engaged in active data collection during this period.

Chapter 4. Methodology

4.1 Introduction

In this chapter the ontological and epistemological frameworks underpinning the research process and how the research questions are answered will be discussed. The implications of the theoretical approach on the methodology, data collection method and analysis, will be outlined in depth to demonstrate and justify decisions made. The complex ethical process and recruitment procedures had a significant impact on the form and format of the research and will be discussed at length. Furthermore, the details of how the analysis was conducted will be delineated. The positionality of the researcher will be discussed and how a variety of reflexive techniques were utilised to prevent professional biases dominating the analysis process and findings. The impact of the COVID 19 pandemic and how it shaped the research project will also be discussed.

4.2 Theoretical perspectives

4.2.1 First steps in identifying an epistemology/ontology.

This section will commence by outlining how the ontological and epistemological paradigm was selected, why this perspective was chosen, other potential approaches considered and why they were rejected. Identifying this multiplicity of perspectives in relation to the care experience was to have an important influence on my later research interests and focus.

Being involved in a research project into the experiences of people living with dementia in hospital allowed me to identify that there were gaps present within the evidence base, in relation to the hospital care experienced by people living with dementia and their carer/s. There was a dearth of qualitative research exploring different hospital processes for these patients, even though there was an abundance of evidence suggesting negative hospital outcomes in relation to care home admissions and delayed discharges (Healthwatch, 2015; Alzheimer's Society, 2016; National Audit Office, 2016; Fogg *et al.*, 2018). I knew that people living with dementia deserved a better evidence base informing their care, and that their experiences and perspectives be acknowledged and understood within the research community, clinicians, and hospital administrations. There was also a requirement for further policy informed by evidence regarding patient and carer experience.

When drafting my research proposal and applying for funding, I implemented a literature scoping exercise. There was limited published qualitative research focusing specifically on the experiences of people living with dementia and their carers during the hospital discharge process. There was also limited research focused on health and social care professional experiences and opinions of the process. There was quantitative research available showing negative associations between hospital stays, poor discharge experiences and adverse outcomes (Fogg *et al.*, 2018; Age UK, 2016; National Audit Office, 2016; Alzheimer's Research UK, 2018). However, the voice of the patient and their carer was largely absent, as most of the studies focused on quantitative data and results.

4.2.2 Choosing a qualitative approach.

This belief in the need for a multitude of voices and perspectives ruled out the possibility of a quantitative project. I had already identified that quantitative research revealed the link between hospital discharge and negative outcomes. However, the absence of the patient or carer or professional experience in the quantitative data meant that the reason for those negative outcomes was not clear (National Audit Office, 2016; Fogg *et al.*, 2018; Alzheimer's Research UK, 2018). Quantitative research methods are based on an ontology that purports there is only one solution, answer, or experience, that can be identified via a rigorous analytic method devoid of subjectivity (Bruce, Pope and Stanistreet, 2017). My previous experience within the NHS as a staff nurse had revealed to me that there is rarely one answer to patients experiencing poor or positive consequences, and that the relationship between patient outcomes, experience, and professional practice, is an extremely complicated one. Further to this, the data available via quantitative approaches, such as analysing questionnaire data, would not allow for the opportunity to explore the individual experiences and perspectives of carers, patients, and professionals in different fields

(Peat, 2002). The decision to focus on wellbeing, a highly subjective term, would not lend itself well to quantitative methods and approaches either. The necessity of a qualitative approach that appreciated the complexity of the discharge process, and the multitude of perspectives from the individuals involved was evident once I decided on the research aim and objectives.

4.2.3 Identifying an appropriate paradigm.

I spent a significant amount of time exploring the different ontologies, epistemologies and paradigms that underlie modern academic research. This was in some ways a bewildering process for a health care professional entering the philosophical sphere of research. Research methods previously taken at face value, such as questionnaires, interviews, and even clinical trials, suddenly took on a plethora of ontological and epistemological dimensions, aspects and questions. Already knowing that I was interested in exploring different perspectives and experiences and that qualitative methods would suit this approach, I began working backwards to try and understand the ontology and epistemology behind what had felt instinctive to me as a novice researcher.

I began to explore the concept of ontology ‘what is the world’ and epistemology ‘how can we know and understand the world’ (Mays and Pope, 2000, p. 17). This is a hotly debated area with differing stances and opinions apparent in different research spheres and fields. The meaning of interpretivism, realism and the epistemologies associated with each differ according to approach and theorist (Flick, 2006; Bourgeault, Dingwall and De Vries, 2010; Silverman, 2013; Mays and Pope, 2020;). It is not within the scope of this research to explore these ideas in depth or answer some of the complex and evolving debates within these fields. I will therefore, outline my own approach which leans heavily on the work and stance of greater theoretical minds that have come before me, and which acknowledges the flawed nature of any theoretical stand point ultimately adopted.

The MSc qualification I completed, prior to embarking on my PhD, included exploring competing paradigms and philosophical approaches within the field of research. I explored the positivist paradigm, the realist paradigm, and the interpretivist paradigm on multiple occasions. Fairly early in these explorations, I rejected the positivist paradigm on the basis that the complexity of the discharge process and the importance of the input of different perspectives from professionals, carers, and patients, make it difficult to identify one solution or one set of facts aimed at recording a single objective reality (Bowling, 2014, p. 136; Mays and Pope, 2020). Further to this, the positivist focus on finding truths that are objective and value free (Mays and Pope, 2000, p. 20; Fallon, 2016) was at odds with my interest in carer and patient experience and wellbeing as a subjective concept. Interpretivism, by contrast to positivism, has a relativist ontology (an assumption that reality is subjective) and a subjectivist epistemology (the researcher is part of the investigation, ultimately influences all findings and values the viewpoint of those being studied) (Bourgeault, Dingwall and De Vries, 2010; Mays and Pope, 2000, p. 20). Whilst positivism and interpretivism stand at opposing ends of the ontological and epistemological debate, most researcher's approach, and paradigm fall somewhere between the two.

I was inherently drawn to social constructionism, a key epistemological approach in qualitative research which is not without controversy. I tentatively explored the tenets of critical realism and symbolic interactionism. I ultimately rejected the critical realist ontology as I found the concept of stratified layers of reality, and the search for causal mechanisms and powers at odds with my desire to listen to the perspectives of professionals and carers and value their experiences (Bhaskar, 1978; Archer *et al.*, 2013;). Although critical realism allows for the agency of the individual, in conjunction with causal mechanisms, I felt the search for invisible drivers of behaviour inherently dismissive of individuals who offer to share their knowledge and insights (Archer *et al.*, 2013). I am also unconvinced that all behaviour and actions are necessarily explained by invisible mechanisms which are somewhat unknowable, and I didn't want to focus my analysis on developing theories related to unseen forces driving processes and actions. I attempted to think about the research project from a critical realist perspective and found that the project became driven by the requirement to identify mechanisms and examples of agency, rather than focusing on the discharge process and the unique insights and knowledge of individuals.

Symbolic interactionism's prioritisation of the individual appealed to me early in the research process (Mead, 1934; Blumer, 1969; Denzin, 1992). However, its overt focus on the individual, and dismissal of the impact of the social structure, ensures that the context of the NHS and social care services become secondary to individual interpretation. Small scale interaction is undoubtably vital in the context of my research project; however, the wider health and social care structure are integral to the focus of the research project. The lack of attention to wider social structures entails that inequalities and power dynamics are overlooked within symbolic interactionism. Such an approach would be unforgivable for a research project exploring a process set within a hieratical organisation, such as the NHS, which wields immense power over people's daily lives. The medical hierarchy is well established theoretically and experienced practically by individuals. Ignoring these dynamics would not have served the project well.

4.2.4 Social constructionist ontology

Social constructionism first emerged from the work of Durkheim (1897) and the concept that there were a set of normative beliefs, accepted by modern societies, that govern the day-to-day behaviour of human beings. This epistemological approach suggests that meanings within society arise from shared human interactions, which in turn are dependent on and reinforced by further interactions (Harding and Palfrey, 1997). Language is particularly central to this process as it is through language that humans communicate meaning and create power structures, particularly around inherent hierarchies, such as legal and medical systems (Derrida, 1970; Foucault, 1973). This paradigm argues that although there is an objective reality upon which science is based upon, it is experienced and interpreted at a subjective level by individuals. For Eisenberg (2009) this leads to the conclusion that there is no universal truth, even in the medical sciences. Instead, belief systems adopted by society and reinforced by institutions, always influence behaviour and medical explanations. This can help explain differences in understanding, behaviour, culture, and opinion, as there is always a multiplicity of different experiences available to the individual, and different belief systems will influence both understanding of and response to events.

Further to this, Berger and Luckmann (1991) argued that subjective meanings often become objectified over time and become part of a shared common world, internalised by individuals, and reinforced by institutions. This is described as 'an ongoing dialectical process of externalisation, objectification and internalisation' (Berger and Luckmann, 1991, p. 149). This approach can be useful in understanding institutions, organisations, professional behaviour, and roles, particularly within established institutions such as the NHS or local authorities.

Several criticisms have been raised against social constructionism, and it has been argued that it becomes trapped in a postmodernist paradigm by reducing reality to language and subjectivism (Harding and Palfrey, 1997). However, these criticisms have been largely addressed by Shotter (1993) who argued that the researcher or individual is part of a social, shared and interactive reality in which social truths can only be discovered by looking at how individuals shape everyday activity, through their interaction within systems. This focus on practices, activities and how procedures are negotiated with others to build shared ideas and meanings, are particularly useful for understanding interactions within the healthcare system between professionals, patients, carers and within institutions, such as in the hospital context. This paradigm allows for the discrepancy between the perspectives and understandings of different health and social care professionals, working in the same context, and patient or carer perspectives. I have outlined in diagrammatical form (figure 6) this experience of reality. This is an allowance integral to my research focus. Figure 6 depicts visually the social constructionist approach.

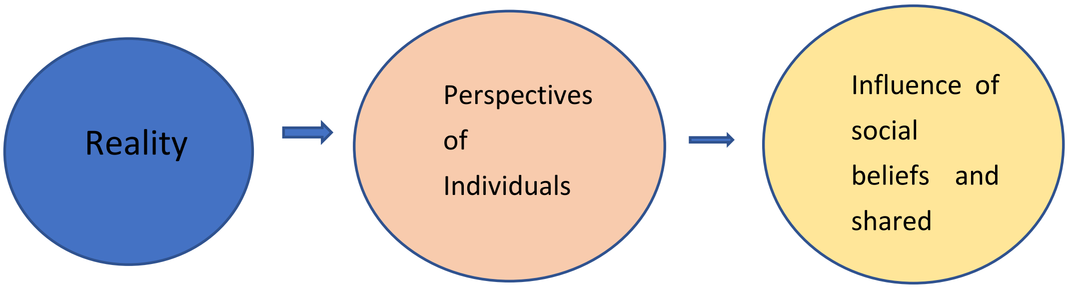


Figure 6. Social constructionism

Social constructionism is a particularly useful ontology for understanding health and social care practice in relation to people living with dementia. This is due to the ways in which ideas around the dissolution of identity, and the eradication of the self for this patient group, have historically been accepted and normalised by both the medical profession and wider society (Sabat and Harré, 1992). The medical model of dementia and its ability to stigmatise the individual has been identified by numerous academics (Sabat and Harré, 1992; Kitwood, 1997), and only recently have these discourses begun to be challenged in both academic discussion and health and social care practice and policy.

In accordance with this approach, the concept of wellbeing has been acknowledged as a subjective notion (La Placa, McNaught and Knight, 2013) with different meanings available in different contexts. Therefore, the factors that ensure wellbeing will have elements of subjectivity for individual patients, and their carers, dependent on their specific needs and circumstances. This has been acknowledged in both academia and health and social care practice, as person centred, individualised care has been adopted as the primary method of interacting with people living with dementia in health and social care contexts (Kitwood, 1997).

4.2.5 Why reject a grounded theory approach?

It is evident from the arguments above that the adoption of a social constructionist ontology allowed me to accommodate a divergence of perspectives, belief systems and behaviour of patients, carers and health and social care professionals within the context of the health and social care system. After deciding to adopt a socialist constructionist ontology, I considered the potential benefits of adopting a grounded theory approach (Glaser and Strauss, 1967; Corbin and Strauss, 2008). I was familiar with the approach having utilised its method on a previous research project. I knew that social constructionism and grounded theory were well suited in terms of epistemology (Charmaz, 2006), and that grounded theory has a well-established place within health research (Mills, Bonner and Francis, 2006; Ralph, Birks and Chapman, 2015). However, my decision to undertake a systematic review at the outset of the research project felt at odds with the spirit and established initial approach of grounded theory. I was also coming to the project with a nursing background and previous experience as a researcher in the field of dementia. Furthermore, my decision to utilise patient and public participation at the outset of the project, and in the design of the interview schedules, did not align with the method of grounded theory (Glaser and Strauss, 1967; Ralph, Birks and Chapman, 2015). Ultimately, I decided that the project didn't align with a grounded theory approach and as the research project evolved in response to the pandemic, I felt this decision to be justified due to the adaptation of the project to pandemic circumstances that would not have adhered to the grounded theory method.

4.2.6 Appreciative Inquiry Approach

I decided to adopt an Appreciative Inquiry approach after reading about the benefits such an approach can bring to a study designed to explore and appreciate the mechanisms of a large organisation, and what changes might lead to improvement (Bushe, 2011; Cooperrider and Fry, 2020). Appreciative Inquiry involves a positive outlook cycle of appreciation and change (Bushe, 2011). The approach aims to identify what works well in an organisation and use these strengths as a springboard for further improvements. The Appreciative Inquiry approach (Bushe, 2007) acknowledges that large organisations are best understood by the individuals that work with and for them, and that you cannot improve an organisation by looking at previous actions, but only by asking what future changes could enhance services, processes, and organisational structures (Cooperrider and Whitney, 2005). It involves a five-stage process and I decided to use the first four stages to support the research project. Definition, discovery, dream, and design were incorporated into the method of the research project which aims to: 'define' wellbeing for carers and health and social care professionals; 'discover' the perspectives and experiences of this population of the hospital discharge process; and asks them to 'dream' of improvements to the overall process. My ultimate role is to begin the process of 'designing' improvements within this thesis and in future research outputs. The 'destiny' (sometimes referred to as delivery) aspect of the cycle, where positive changes are implemented in practice and policy, will take place outside of the scope of the thesis and through the implementation of future collaborative research projects.

This approach positions carers, and health and social care professionals, as best placed to advise or ‘dream’ of improvements to the hospital discharge process due to their specialist experiences, acumen and knowledge. Furthermore, the open nature of the change process allows for the design and destiny/delivery aspects of the research project to be achieved outside of the thesis, and in conjunction with health and social care partners in an un-prescriptive format. Additionally, the Appreciative Inquiry approach aligns neatly with the social constructionist paradigm, as it accepts that institutions and organisations are formed by their participants, and able to enact change as fluid, constructed entities through human action (Cooperrider and Whitney, 2005).

In this research project, I have adopted the Appreciative Inquiry approach as a theoretical perspective and guiding influence (Cooperrider and Fry, 2020). This was particularly pertinent after identifying in the systematic review that there was a research gap in relation to positive discharge experiences. The decision to identify what is currently working well within the discharge process to support the wellbeing of people living with dementia and their carers guided the focus of the project, data collection, analysis process and development of a framework.

Appreciative Inquiry’s ability to identify and build upon a processes’ strengths was appropriate for answering the research questions: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?* I will identify throughout the thesis the times when I was guided by the Appreciative Inquiry approach (Cooperrider and Fry, 2020) in designing the interview topic guides, analysing the data and developing the framework. The Appreciative Inquiry process is depicted in figure 7.

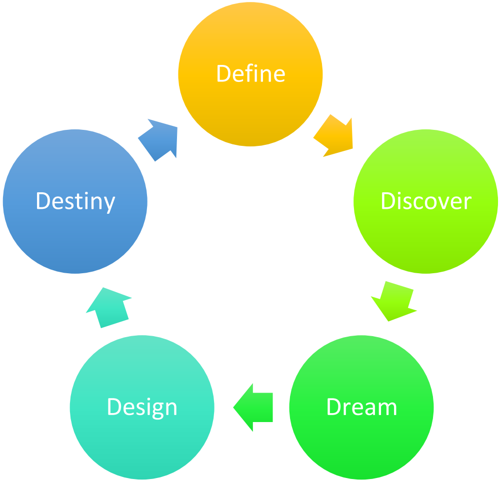


Figure 7. Appreciative Inquiry cycle (Cooperrider and Whitney, 2005)

4.3 The qualitative method

4.3.1 The ethnographic and interview method

Once I decided to adopt a social constructionist paradigm utilising the Appreciative Inquiry approach, I turned to consider the most appropriate qualitative method or methods to adopt. I chose to adopt a flexible case study design (Yin, 2012) because of this method's ability to enable the study of a phenomena in context, and to account for a discharge process that can be messy with blurred boundaries. The 'case' boundaries of my research project are broader than the usual case study unit. This non-conventional format was necessitated by the nature of the pandemic, and the inability to access settings in the usual manner of a qualitative research study. In identifying my research as a case study, I heeded the work of Yazan (2015) who explored the juxtaposing approaches of different theorists to the case study format, and ultimately adopted the approach of Merriam (1998, p. 148), who describes "an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit". The case study in my research is the integration of the discharge process and the process of the impact of the pandemic regulations. The period in which the research project took place is unique. In 2020 and 2021 the process of hospital discharge was markedly different to the situation in 2019 and 2022, when the impact of the pandemic and pandemic regulations either did not exist or were regulated to a more minor consideration. If I implemented the same research project today, the data collected would be significantly different due to the abatement of the pandemic. On reflection, I have come to understand this modified case study as a neo-case study which fits the requirements of this specific period. The case study method's ability to identify explanatory aspects of the hospital discharge process, a process that is extremely complicated in its many characteristics, appeared ideal to enable the exploration of the breadth of the process, from the hospital to the community setting, during this unique period (Creswell and Poth, 2018).

I chose the ethnographic and interview method as this combination has many identified benefits. Implementing both interviews and an ethnography allows the weaknesses of the individual methods to be addressed by the strengths of the complimentary method. In healthcare research, the interview method can help researchers access the opinions and beliefs of individual patients concerning their treatment or subjective healthcare experience (Seale, 2012). However, in critique of the interview method theorists operating within a positivist framework have identified the possibility of the researcher distorting the interview data through misleading or biased questions (McCracken, 1988; Alshenqeeti, 2014). This criticism is of limited applicability to the ontology of this project. Another issue is the reliability of data derived from the interview. Theorists researching within a constructionist perspective have argued that there is no route within the interview process to access the thoughts or experiences of participants, only co-constructed narratives (Silverman, 2017). Interviews are characterised as merely reflections of 'cultural convention' (Denzin and Lincoln, 2018).

The ethnographic method, used in conjunction with interviews, allows this criticism to be addressed. Ethnography can allow researchers to fill the contextual spaces left by interviews and quantitative research. This is achieved by allowing 'social processes observed and […] social meanings,' to be identified in context (Hammersley, 1992). Ethnography can also identify discrepancies between actions discussed in interviews and observed behaviours (Agar, 1996). Further to this, ethnography can answer the criticism that interview data is a construction devised between the interviewee and interviewer (Rapley, 2001). However, ethnography has been similarly criticised (Clifford *et al.*) as being a construction of the ethnographer alone. Therefore, it is open to researcher bias, misunderstanding and fabrication (Agar, 1996; Jones and Smith, 2017). However, Hammersley (1992) and Rashid, Caine and Goez (2015) have answered these criticisms. The use of a research diary and explicit statements, detailing both the research context and areas of potential bias on the part of the ethnographer, are identified as removing these obstacles.

I decided that combining the ethnographic and interview method would allow me to address the research aim and objective effectively. Interviews with carers and health and social care professionals would allow for insights into their perspectives concerning the factors that ensure wellbeing during the discharge process. I identified that some people living with dementia would be unable to take part in interviews and that the ethnographic method would facilitate their inclusion in the data. The ethnographic method also allows the observation of the discharge process in real time, and for the actions and behaviour of carers, patients, and staff to be viewed in context. Combining these two methods would create a comprehensive and detailed overview of the hospital discharge process, and the holistic factors that ensure wellbeing is maintained for this patient and carer group.

However, along with the global qualitative researcher population, I was compelled to adopt other measures due to the restrictions associated with the COVID-19 pandemic. Social distancing created barriers to traditional qualitative methods and provided new opportunities. My decision to adopt a case study approach was validated as the wide-ranging impact of COVID-19, and the public health measures adopted in response, meant that my research findings became partly about the experience of individuals living with dementia, and their carers, of the hospital discharge process during the COVID 19 pandemic. Reflecting this unique set of circumstances was supported by the flexibility and context specific focus of the case study method (Merriam, 1998; Yin, 2012; Creswell and Poth, 2018) which allowed the impact of the pandemic to become part of the case studied.

4.3.2 The impact of COVID 19 on the methods utilised.

At the end of my maternity leave and as I returned to the research study, I began the process of changing the focus of my PhD to reflect the changes occurring throughout society in response to the COVID-19 pandemic. The hospital discharge process itself had been profoundly altered by the guidance issued by the UK Government (Department of Health and Social Care, 2020a). New guidelines prevented visitors, including informal carers, from supporting people living with dementia in the hospital setting. I began to wonder how this would be impacting on the wellbeing of those patients who would usually experience open visiting with their relatives and carers. I also wondered how this would be impacting on carers and relatives used to supporting their relatives daily, and who were suddenly without contact. I speculated about how different health and social care professionals might find their roles altered, and how this might impact their ability to support the wellbeing of patients and carers during social distancing, and particularly in the light of Personal Protective Equipment (PPE) requirements. I felt that I could not ignore the impact that new guidance might have on professional roles and their ability to support patient and carer wellbeing.

I was also aware that the 'meaning' of the NHS and the role of health and social care professionals within the minds of the public, and the media had changed. The 'clap for the NHS' was a focal point of the English lockdown and the much-maligned NHS underwent a transformation in image. Further to this, the focus on shielding the clinically vulnerable, particularly the older section of the population, raised the profile of areas of the population often ignored by the media, including carers and people living with dementia. The media scandal regarding the Government's decision to discharge patients to care homes without receiving a COVID 19 test, and the subsequent large number of tragic deaths, highlighted this population and the vital role played by the hospital discharge process. These changes in 'meaning' have continued throughout the pandemic and, as I write this on 'Freedom Day' July 19th, 2021, the importance of the vulnerable population has once again shifted to being of secondary concern as society irreversibly 're-opens,' and COVID 19 infection numbers soar. The imagery utilised by the UK government during the corona virus pandemic continued to shift and morph as social meaning and understanding changed. As I further edit this thesis in March 2023, it is difficult to recall this period fully, as the pandemic has been largely consigned to a concern of the past.

The images below typify the ‘branding’ of the pandemic to the population at large from a terrifying and dangerous illness to a minor threat.

Figure 8 depicts the early pandemic images.

Figure 8. Stay Home, protect the NHS, save lives. April 2020

Figure 9 is a visual depiction from later in the pandemic representing the change in approach and visual narrative.

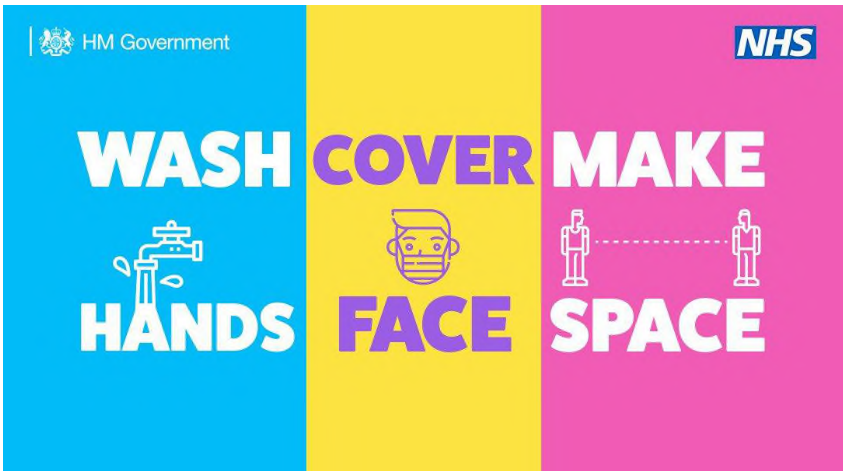


Figure 9. Hands face space. August 2021

These continuous changes in meaning bolstered my decision to adopt a social constructionist ontology. The hospital discharge process altered both practically and in relation to social meaning. No longer just a way to ‘empty hospital beds,’ as it had been previously characterised, the importance of robust planning, the focus on safety, and the importance of prioritising the person being discharged from hospital, and their family, were evident. The process, which has often been overlooked as an addendum to the important medical treatment occurring within the hospital, was revealed as potentially the most important aspect of the hospital stay and not the afterthought.

I realised that all these changes would radically alter the nature of my fieldwork and ultimately my thesis. I accepted that an ethnographic study would not be possible within the contextual period of my PhD. I began to explore alternative methods for achieving the aims of my research project within the time frame of the PhD. I decide that the scope of the research project would need to incorporate the impact of COVID 19 measures on the discharge process, and the legacy that the measures would have in order for the findings of the research project to be relevant, and valid, in the ongoing pandemic and post-pandemic period.

4.3.3 Online interviews and the digital ‘field’

I began researching the option of virtual interviews via mediums such as Teams, Zoom and Starleaf, alongside telephone interviews. I had limited understanding of these methods and found the published literature available very restricted. There was an established body of research pertaining to telephone interviews (Sturges and Hanrahan, 2004; Novick, 2008; Holt, 2010; Irvine, 2011; Irvine, Drew and Sainsbury, 2012; Drabble *et al.*, 2015; Fischer *et al.*, 2015) but significantly less literature available in relation to interviews via digital means. The technology to support video calling was available pre-pandemic but only used by professionals in very limited circumstances. Skype, WhatsApp, or Facetime were the dominant mediums used and for most of the population these methods were not a key part of their daily communication with others.

The uptake of digital means of communication, facilitated by lockdown and isolation measures, enabled the option of digital interviews to be considered. The unknowns and potential pitfalls of using the digital medium were outweighed by the ability to facilitate interviews in a context where face to face interaction was not possible. The technology to facilitate interviews developed significantly during the life of the research project. The mediums of Zoom and Teams became more robust as they were used more frequently in the population's work and home life. Using these technologies for interview purposes presented me with a learning curve experienced by all researchers who turned to these mediums during the pandemic. Significant time was spent learning how to operate the different mediums and schedule recordings and transcriptions. At one point, an amendment to the study had to be submitted as I had not realised the recording possibilities of Teams and wished to use this medium.

The available literature detailing the impact on the data of using these mediums was limited. When I was designing my study in May 2020, articles pertaining to interviews carried out online were largely limited to discussions around the use of Skype (Cater, 2011; Hanna, 2012; Deakin and Wakefield, 2014; Seitz, 2015; Lo Iacono, Symonds and Brown, 2016), and the bonuses and drawbacks of this earlier technological interface. As outlined above, the decision to use online mediums was not driven by theory or findings from other research projects but by necessity. Over the next section, I will discuss why I have come to believe that digital interviews, via a medium such as Zooms or Teams, are equal in value and even arguably superior to face- to- face interviews, which have traditionally been considered the gold standard in qualitative interviewing (Deakin and Wakefield, 2014). I will also discuss the benefits of telephone interviewing, a medium which I found immensely rich and dynamic.

Interviewing via digital means opens new possibilities (Lo Iacono, Symonds and Brown, 2016). The potential of digital mediums, such as Zoom and Teams, for wider and more diverse recruitment has been previously appreciated along with the potential to exclude individuals without the technological know-how or access (Cater, 2011; Jenner and Myers, 2019). This was sadly the case for myself as individuals with dementia often find it challenging to make sense of screen-based technologies, and the ethics of assessing capacity via a digital medium are questionable (Deakin and Wakefield, 2014). I decided early in my assessment of online interview mediums that no interviews with individuals with dementia would be possible. This is a serious criticism of online methods as it could be argued that they are discriminatory, and where possible, face- to- face interviews should go ahead to prevent the impact of digital inequality.

Another drawback of the online interview includes the presence of technical issues connected to working the technology and obtaining sufficient broadband width (Seitz, 2015; Archibald *et al.*, 2019; Howlett, 2021;). Technical aspects can be challenging for both the researcher and the participant who must master these mediums effectively. I spent a significant amount of time learning the technical differences between Teams and Zoom and how to function across both platforms. As many other researchers have, I found many technical issues were overcome easily with sufficient forward planning (Jenner and Myers, 2019). I identified that the ability to record interviews easily, re-watch them at the touch of a button, and create full transcripts instantly was of significant benefit. Transcripts produced often require significant editing but are still an efficient way of recording the dialogue of an interview. Being able to re-watch an interview, phrase or segment instantly was extremely useful during the analysis period. I was able to forward the video to the moment analysed and watch back the interviewee's response. Furthermore, I was able to assess my own interviewing technique. This was often a painful process, but ultimately a valuable one and a learning opportunity.

These benefits are balanced by the reality that concerns about data protection often exist in the online context (Howlett, 2021). The use of online mediums leads to sharing data/personal information with a company, such as Microsoft, as part of the process. However, I found that everyone I contacted who chose to use platforms, such as Zoom or Teams, already had an account and was already choosing to share their video calls with these mediums. The ease of being able to schedule an interview was fantastic and this has been widely recognised previously (Cater, 2011; Archibald et al., 2019; Jenner and Myers, 2019). I did not have to concern myself with interview spaces or travel, vital during lockdown periods, and this allowed participants to simply take an hour from their day to take part.

Loss or lack of rapport has often been cited an issue arising from the online interview (Seitz, 2015; Weller, 2015; Lo Iacono, Symonds and Brown, 2016), but this was not something I experienced during my interviews. I hypothesise that the stilted rapport finding could be linked to an earlier Skype context before the general population were familiar with online video calling. A number of recent articles have reported that rapport has not been an issue while using Zoom. I, therefore, suspect this may be an outdated criticism (Deakin and Wakefield, 2014; Archibald *et al.*, 2019). Alternatively, it could be that due to the ethical requirement to conduct a detailed consent discussion with carers before the interview took place, alongside my approach of having an informal chat with professionals before scheduling an interview, I developed rapport during these earlier conversations and that transferred to the interview itself.

A number of researchers have identified that some participants prefer the online interview for a multitude of reasons (Archibald *et al.*, 2019). Howlett (2021) has discussed the ability of the online interview to re-set the power dynamic of the researcher- participant relationship and place the participant in a powerful position. I agree with this assessment, and I believe that the utilitarian nature of the video call has the potential to ensure that participants maintain dignity and agency during the research process.

Table 7. Online interviews benefits and drawbacks

Table 7	
Organisational ease (geographical and temporal)	Potential discrimination including access to technology, vulnerable groups
Development of rapport	Loss of rapport
Depth of interview	Potential loss of depth of interview
Technological benefits	Issues with technology

In the preceding section, I outlined the challenges but also benefits of the online interview and they are delineated in Table 7. I would like to address some of the criticisms of the telephone interview, a medium chosen by several of my participants. I empowered participants to choose the medium they preferred for the interview (video or telephone), to ensure their comfort. I was sceptical of the utility of the telephone interview in comparison to the online video interview. However, in contrast to other researchers (Irvine, 2011; Irvine, Drew and Sainsbury, 2012; Rowley, 2012), I found no issues with the depth or length of the interview or in the building of rapport. I found that the removal of the face-to-face element added anonymity to the phone call which led to in depth conversations lasting more than an hour.

It has been previously identified that telephone interviews lack the contextual depth of the face-to-face interview due to the absence of body language (Jenner and Myers, 2019). However, I found it easy to identify emotion via tone and subject matter. There were occasions when I did have to ask additional questions to safeguard a participant, as it was difficult to determine if a participant was making an offhand comment or genuinely distressed. I must admit that some of the richness of the data that would have been offered via a video interview was lost in the telephone interview. It could be argued that telephone interviews do not offer as robust a safeguarding framework. This is an important consideration when interviewing participants about emotive subjects.

I decided to implement two separate studies using telephone and online interviews. One study involved interviewing carers about their experiences of the hospital discharge process and the support available to enable and support patient and carer wellbeing. The other study focused on the views and opinions of health and social care professionals regarding supporting carer and patient wellbeing during the discharge process.

4.3.4 Sensitive interviewing

Health and social care professionals were often passionate about their practice and ensuring positive experiences of the discharge process for people living with dementia and their carers. However, their manner of conversation would often be impartial and objective. Interviews with carers were very different. Some carers had experienced very poor care for their relative both in the hospital setting and during the discharge process. Some carers expressed significant grief and guilt due to their experiences of trying to navigate the health and social care system. I discovered very early in the interview process that even consent discussions could become emotional.

One of the ways I navigated this was by empowering participants to choose the medium and steer the main discussion points of the interview. I devised questions in the manner of a semi-structured interview (an example of the topic guide for carer interviews is available in Chapter 14), but I made it clear to participants that the interview would focus on what they believed was important about their experiences and would only cover topics they were comfortable to discuss and believed were vital for understanding their experiences. I utilised a topic guide as a prompt but allowed the participant to direct the conversation.

The benefit of the semi-structured interview is that it provides a guide to the interview procedure, and allows for greater comparability (Barriball and While, 1994) between participant answers. The flexibility to change the question format, order and focus, according to the needs of the interview participant (Kallio *et al.*, 2016), was a useful attribute during the interviews themselves. As the interview developed, I would refer back to the topic guide and probe the participant in relation to follow up subjects.

I drew on the literature available regarding the process of sensitive interviewing and utilised the findings of other researchers to guide my approach to the interview process. Foremost, the importance of demonstrating empathetic and sensitive questioning was vital to my interview technique (Dickson-Swift *et al.*, 2007; Elmir *et al.*, 2011). I asked questions in an open manner that allowed participants to answer according to their preference, for example, ‘can you tell me about your recent experience of when your relative left hospital.’ I allowed participants to talk about their mental health and wellbeing, but I didn’t probe if they indicated high levels of distress concerning a topic. Sometimes I asked questions in an indirect manner to allow participants to choose what to reveal, for example, ‘So you find X is a good source of support?’

I was aware of the importance of creating a safe and comfortable environment for the interviews to take place (McCosker, Barnard and Gerber, 2001; Elmir *et al.*, 2011). The subject matter discussed could be extremely sensitive. Participants had often experienced the bereavement of a parent or been involved in the decision to admit a parent to a care home. Several participants expressed guilt associated with decisions made and ongoing feelings of grief and depression. The consent discussions I held with participants allowed me to develop a rapport (Elmir *et al.*, 2011) prior to the interview, and I determined that this created a more comfortable environment during the interview. I utilised the principles of reciprocity to further create a secure environment and build empathy and understanding between myself and the participant (Booth and Booth, 1994; Corbin and Morse, 2003).

I often shared details of my own experiences to ensure that the participant was not in a position where they always gave and I always took, without some equality in the relationship. This is an approach that has been documented as integral to the development of trust within the interviewer/participant dyad. The sharing of information by the interviewer has been characterised as vital to ensuring equity within the interview space (DiCicco-Bloom and Crabtree, 2006). At the close of the interview, I used the empathetic skills developed as a staff nurse to assess the level of distress visible in participants. I often checked what their plans were for the rest of the day and that they would not be alone. I checked in with participants at some point after the interview to return a copy of the consent form to them and ensure that they were not too distressed by their participation.

4.4 Value, quality, and reflexivity in the research process

The next section of this chapter will outline the ways in which I engaged with the concepts of validity, reliability and trustworthiness when designing, implementing, and documenting the research project (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2013; Korstjens and Moser, 2018). These terms can be used interchangeability within the qualitative research sphere and are sometimes replaced by concepts of credibility and dependability (Guest, MacQueen and Namey, 2011; Noble and Smith, 2015). Choosing how to engage with these concepts is vital to ensuring the quality of research findings and for allowing other researchers to understand the value of the research product. I also engaged with the importance of ensuring rigour by explicitly outlining my method and approach early within the research design to guarantee clarity (Mays and Pope, 1995).

4.4.1 PPI (Patient and Public Involvement)

Modern health and social care research should be relevant and meaningful to the individuals for whom the research is ostensibly implemented (The King's Fund, 2018). The Wanless report (2002) demonstrated the need to ensure that members of the public were highly engaged in the delivery of health and social care services and integral in the design of service provision and research. This is especially true of research in the field of dementia where individual rights, preferences and opinions, have been historically overlooked by health and social care structures (Kitwood, 1997).

Qualitative researchers have recognised the many benefits of including patients and the public in the planning and delivery of research to ensure it is both designed and implemented to reflect the concerns and experiences of key stakeholder groups, including carers and patients (Brett *et al.*, 2014). Correspondingly, the NHS has recognised the value of the input of patients and carers with expert experience in their field. Policy documentation has reflected the need for stakeholder and service user involvement at all levels of research development (NHS England, 2017). Research regulating bodies such as the Health Research Authority (HRA) insist on relevant and meaningful PPI as an integral part of any study seeking HRA approval. During the COVID 19 pandemic, the HRA even adopted a fast-track service to ensure the involvement of relevant members of the public for all proposed research (NHS Research Authority, 2021).

However, PPI is often criticised as tokenistic and a box ticking exercise, with members of the public simply asked to provide feedback or invited to meetings (Minogue et al., 2005; Brett *et al.*, 2014). Furthermore, ensuring genuine and meaningful PPI can be a complicated process as the thoughts and perspectives of participants may differ to the opinions of the research team. The PPI relationship may become strained if the perspectives of all are not respected (Reed, Weiner and Cook, 2004). I recognised the value of PPI early in the design of my research, and the benefit of seeking and respecting the opinions of a wide range of stakeholders, including carers and professionals in health and social care.

I consulted with a small group of carers to listen to their positive and negative experiences of the hospital discharge process and the support available during this process. Listening to their stories and insights helped shape my project's focus on the wellbeing of carers in particular. It was clear that wellbeing was not addressed as a priority during the discharge process. I found the lack of attention to both patient and carer wellbeing during such a difficult and complex process concerning. The carers I spoke to mentioned that the absence of emotional and practical support during the discharge process was a significant problem.

I also consulted with several different professionals during one-on-one meetings including specialist nurses, discharge co-ordinators, and social workers, to ask their opinion of the research topics that would aid their daily practice. These conversations allowed me a broad overview of the acute hospital discharge process and the differing priorities and perspectives of professionals. This enabled me to design the professional interview study to include questions on topics that were important to, and relatable for, professionals and which reflected their daily practice.

Later in the research process, I again consulted with carers regarding the design of the participant information sheets to be used in the recruitment of carers as participants. The feedback to simplify the jargon used in the information sheets, and ensure a more readable layout, helped me to design more accessible documents. Unfortunately, changes in the nature of the research project due to the pandemic, the need to include standardised General Data Protection Regulation statements, and input by the NHS Research Ethics Committee, meant that the final participant information sheets were not as accessible as I would have wished.

4.4.2 Quality in the qualitative research process

The difficulties faced by qualitative researchers when confronted with the quantitative standards of validity, reliability and rigour, have led theorists to explore ways of maintaining quality in qualitative research that does not lead to positivist reductionism but also escapes the criticism of outright relativism (Lincoln and Guba, 1985; Seale, 2002; Horsburgh, 2003). The nature of quality itself is controversial in qualitative research where divergence, context and uniqueness are celebrated, while uniformity and standardisation are rejected (Braun and Clarke, 2013). In health-related research, such as the research project I embarked on, being able to justify any findings or recommendations is crucial to the utility of the research findings and therefore quality, even as a disputed measure, is an important consideration.

At the beginning of my research journey, I examined different ways of ensuring quality in the qualitative research process. It appeared to me that reflexivity (Horsburgh, 2003) would be an integral element in maintaining the value of any findings from the research. My positionality as a nurse, and my background as a researcher in the field of dementia, entailed that the influence of my perspective on the research method, analysis, and findings, would be considerable. Lincoln and Guba (1985) identified that all research findings and theories are the product of the interaction between the researcher and participant and, as such, they are situated in the context and values of the two parties. (Lincoln and Guba, 1985; Sandelowski, 1993; Creswell and Miller, 2000; Silverman, 2013). Therefore, the importance of detailing my assumptions and perspectives and reflecting on how these may influence the methods I used, and the analysis I conducted, was crucial to the research process (Creswell and Miller, 2000). That is not to say that outlining the bias and influences I have will negate their impact on the research findings, but adopting a transparent approach will enable the reader to judge the findings in context. I outline my perspective further in the reflexivity section of this thesis.

The established approach to maintaining the quality of qualitative research was outlined by Lincoln and Guba (1985). This approach which focuses on credibility and trustworthiness aims to lay bare the workings of the research process, and researcher, to ensure clarity in the qualitative process and avoid opaque methods and findings that are difficult for other researchers to evaluate. The ‘authenticity’ of the findings is crucial both in terms of participant and researcher input and the analysis process (Creswell and Poth, 2018). This approach includes member checking, triangulation, exploring deviant cases, transferability, ensuring by re-reading transcripts that findings accurately reflect data, and maintaining transparent audit trails. My research, while constructionist in epistemology and qualitative in method, is aligned with the field of health research. Therefore, maintaining quality and ‘truth’ within the method, analysis and findings is an important consideration (Seale, 2002).

Qualitative research must be transparent in all aspects to enable the actions and thought processes of the researcher to be available to the reader and enable the assessment of the findings of the research.

I originally planned to implement triangulation of method in relation to data collection by combining the ethnographic method with the interview technique (Flick, Kardorff and Steinke, 2004). However, this became unachievable during the pandemic when no one could enter the hospital outside of clinicians and patients. I ultimately adopted a more informal version of triangulation by obtaining interviews with both carers and professionals, reflecting multiple perspectives, and enhancing the overall picture of the hospital discharge process. This softer version of triangulation ensured that the experiences of different sides of the process are visible in the data, allowing for a more nuanced depiction of the discharge process, which reflects the juxtaposition of opinions and viewpoints both lay and professional.

I spoke with professional participants on at least two occasions. Once in the informal discussion and once during the interview. This allowed professional participants time to think over their responses and moderate their thoughts and words before the formal interview process. I believe this has enhanced the quality of the data collected as professional participants were able to think through their perspectives and opinions and re-assess the information they chose to convey. The drawback of this approach was that participants could change how they formulated their answers away from their first reactions. However, I believe that allowing participants time to think about their response is valuable for collecting data that reflects their considered opinion.

The approvals from the NHS dovetailed well with the concept of developing a clear audit trail. Ensuring an audit trail includes the provision of both documentation detailing the actions taken, and the decision making and thought processes of the researcher during the research process (Carcary, 2009). I adopted a research diary which I wrote in every day during my journey as a PhD student. The entries were not always long or concise and the diary itself also contains personal notes and details about my life during this period. The entries often reflect my first thoughts and musings and to-do-lists. This reflects the reality of the qualitative research project and the iterative nature of evolving concepts, ideas and plans. Nothing about my research project remained static, it was in a continuous state of evolution due to the uncertainty of the pandemic, and the adaptations I made to address the limitations, but also possibilities, of the context.

4.4.3 Reflexivity

Engward (2015) outlines some of the challenges of reflexivity, where outlining one's positioning must be balanced with the need to prevent the research becoming solely about the author and their history. Finlay (2000) indicates the importance of outlining bias, perspectives and experiences, to allow the reader to identify the impact on the analysis process and findings. I outlined my personal experiences and positioning at the introduction of this thesis, but I will reflect further at this point in the methods section.

Throughout the research process, I was aware of the impact of my experiences, as a health care professional, on my interpretation of the data. I believe that this led to a rich and full understanding of the discharge process based on my ability to understand the context of participant narratives. However, my understanding of the challenges of the nursing role meant that I was instinctively drawn to validate the perspective of the nursing participants and support their world view, and this must be acknowledged.

As outlined in the opening chapter, I am also, in a limited sense, a carer for my grandfather who is diagnosed with vascular dementia and Alzheimer's disease. I sometimes advise, but more importantly, listen to relatives who are immediate carers to these family members. I am aware of the physical and emotional cost of these roles. Therefore, I believe that I have a comprehensive overview of being both a carer of someone living with dementia, and a health professional. I believe that I am able to maintain a reasonable balance between both perspectives and allow my understanding of both perspectives to further illuminate the context of the findings.

Alvesson and Skolberg (2009) identify four levels of reflexivity that a researcher can employ. The first level is gained by ensuring that they do not dominate the data collection process by asking open questions and allowing participants to guide the topic. I demonstrated the data collection interview technique, and the ways in which I aimed to democratise the process, in the previous section outlining how I employed sensitive interviewing.

During coding, Alvesson and Skolberg (2009) identify that is it important to recognise any data not included in the findings and recognise where there are deviant findings. I outline in the findings section where there are alternative findings to give both a balanced view of the data and prevent the cherry picking of findings that suit my arguments. The third level is obtained through the clarification of the political-ideological environment. Within the introductory chapter I outline many of the ideological approaches underpinning this research project and reflect on this further within the discussion section of this thesis.

Lastly, Alvesson and Skolberg (2009) identify that researchers must be aware of the way they present their research and the words and language chosen. I am explicit concerning the use of the Appreciative Inquiry approach and that many of the linguistic choice are supported by wider literature identified in the systematic review and the person-centred care ethos within this research sphere. I believe that throughout this thesis I have been reflexive in the presentation of data collection and findings, such that the reader may understand my perspective, and its impact on the project conclusions.

4.5 The ethical process

The protection of the rights of participants is one of the most important aspects of any research project (Bourgeault, Dingwall and De Vries, 2010). This is increased where there is 'institutional vulnerability' due to being linked, through employment or being a patient or carer, to a large health and social care organisation (Bourgeault, Dingwall and De Vries, 2010, p. 591). In this section, I will outline the complicated process of obtaining the ethical approvals needed for two separate qualitative studies, from the NHS and local hospital Research and Development departments, during a pandemic.

The context of the pandemic entailed that a pragmatic approach had to be taken to the data collection process for this project. The decision to have two separate studies, one including professional participants and one including community-based carers, was due to the limited time available in which to undertake the project, and related concerns regarding feasibility during the English Lockdown periods. It was unknown during the early stages of the pandemic in 2020 which studies would be considered ethical in light of the requirement for remote interviews and remote consent procedures. It was decided to have two separate studies to enable the commencement of data during this period of uncertainty.

4.5.1 Re-designing the protocol and research project documentation. Obtaining approvals

Once I had decided on the medium of digital interviews, the next step was to re-design the protocol and documentation for the research project. I re-visited the research proposal and began the process of re-writing the protocols for the two separate research projects. I decided to adapt the original research project which involved interviews with health and social care professionals and adjust it to suit the digital interview medium. However, I incorporated exploring the impact of COVID 19 on the discharge process into the objectives of the study. The value of the Appreciative Inquiry approach (Priest *et al.*, 2013) was evident during the re-design of the topic guides for the semi-structured interviews (please see Chapter 14 for the carer and professional study protocol). The guides were designed to focus on aspects of the discharge process that supported wellbeing in accordance with the strengths approach (Cooperrider and Whitney, 2005), and to account for the impact of the COVID 19 pandemic.

Being unable to implement an ethnographic study based in the hospital setting due to the impact of COVID 19 was disappointing. I felt the loss of the rich data that such a study would have afforded and the ability to observe hospital discharge processes in person. However, I quickly realised that a unique opportunity to collect data during pandemic conditions had arisen. My experience in many ways echoed the pandemic experience of professionals, patients, carers and relatives, of the hospital discharge process. Face- to- face meetings were not taking place and discussions were occurring over the phone or via digital mediums. Therefore, the method of my research project mirrored the method by which discharges were being organised in the hospital during this period.

I began to appreciate the opportunity to collect data pertaining to the pandemic experience in real time, and the prospect of incorporating the impact of COVID-19 on the discharge experience into my research project. I decided that interviews via phone and digital mediums with the carers of people living with dementia would offer the opportunity to explore the discharge experience, whilst protecting the safety of participants and adhering to social distancing legislation.

I recognised that it would not be possible to conduct interviews with people living with dementia via phone or digital mediums. Touch and face- to- face interactions are vital for capacity assessments and ensuring participant wellbeing during the interview. This would not have been possible via remote methods. The complexities of technology, and the sensory and memory challenges that people living with dementia face, would have made interviews extremely challenging. It would have been unlikely that such interviews would be considered ethically sound. Due to the limited time available for this project, and the uncertainty of the early phases of the pandemic, when drafting the ethical approval application in May 2020 it was not believed that ethical approval would be given for a remote methods project which included people living with dementia. This is due to the capacity assessment that is required from NHS research ethics committees. I was not certain that an online study, with a remote consent protocol, would be granted approval during this time. Later in the pandemic, it became apparent that ethical approval would be granted for studies taking place remotely, but this was not known in early 2020 when technologies, such as Zoom and Teams, were only beginning to be understood and used in the research context.

Further to this, it would not have been ethical to ask people living with dementia to recall a historical period when they were in hospital and very unwell. Due to the topic of hospital discharge, it was likely that people living with dementia would have been too unwell to be included via digital means. Many of the carers that I interviewed noted that the person they cared for had been very unwell with COVID-19, and several individuals had died in the period before the interview. One potential carer participant withdrew from the study as the person living with dementia began to die during the hospital discharge process itself. Some of the individuals living with dementia had become residents of care homes following their hospital admission. It would not have been possible to access individuals living in care homes during this period. Relatives themselves found it impossible to access their loved ones. It would not have been ethical or feasible to include unwell people living with dementia in this study during this period.

The loss of the voices of people living with dementia is a significant absence within the research project. The ethnographic observations and potential interviews would have incorporated their voices into the data collected. This meant that the data collected became primarily about the experiences of health and social care professionals, carers and family members, and their perspectives of the discharge process for people living with dementia. This limitation is acknowledged throughout the thesis and is an unavoidable consequence of the COVID 19 pandemic on the data available for collection. However, the loss of such voices enabled the research project to focus more thoroughly on the experience of carers during this period. It leaves scope for future research projects to explore the topic with people living with dementia exclusively, preventing such a project from being distracted by carer input.

It was difficult to access many of the professionals involve in the discharge process during this period due to the pressures that the NHS were experiencing. Interviews were regularly cancelled due to the absence of colleagues or workloads being too high. Accessing spousal carers was also difficult due to the inability of carers to access any respite which would have allowed them to take part in an interview. Interviews took place sometimes with the person living with dementia asleep in another room or in the same room with the carer breaking away from the interview to provide care at times.

I applied to the HRA for approval for the re-designed protocol and documentation for the interview study involving health and social care professionals. I also applied for a letter of access and approval from the Research and Design (R&D) department at Newcastle Upon Tyne Hospitals NHS Foundation Trust. Embarking on this task remotely was challenging and involved many hours emailing different departments and individuals to identify the required steps to complete the task. I received HRA approval in

September 2020 and R&D approval in October 2020, alongside the required letter of access. I submitted an amendment to the research project in January 2021, after finding that I had omitted to include visual recording of interviews via Teams to the original consent form, and participant information sheet. University ethical approval was issued in September 2020 due to the low risk of the research project.

4.5.2 Research Ethics Committee approval

I identified that the study involving interviews with carers and volunteers required a proportionate review from an NHS Research Ethics (REC) Committee. I submitted the application in October 2020 and attended a Zoom qualitative REC meeting in November 2020. The REC decided that although the study was eligible for a proportionate review, they requested attendance at a full REC meeting. The REC delivered a provisional favourable opinion in November 2020 but required further transparency around GDPR, student sources of support and consent discussions.

Further to this, documentation was revised, and I developed a distress protocol and confidentiality protocol as requested by the REC. These were welcome additions to the protections available to participants which were built into the study. As a novice researcher, they gave me a road map of the actions necessary to protect both myself and my participants. I remain grateful to the REC for their input as I found their additions to the study helpful and supportive when faced with distressed participants during the data collection period. In February of 2021, the final favourable opinion was received. Ultimately, the involvement of the REC ensured that the final study was ethically robust and designed to support the wellbeing of all participants.

4.6 Data collection

4.6.1 Interview period

Data collection took place between December 2020 and October 2021. Participants were interviewed via telephone, Teams or Zoom, and transcripts were produced via Teams, Zoom or from recordings. When interviewing professionals, informal conversations took place before the interviews. All discussions and interviews took place via Teams and Zoom. This had a subsequent impact on the data collected during the formal interviews, as I had loosely discussed the topics explored in the interview previously. Health and social care professionals often responded in different ways to questions asked during the interview itself, in comparison to when the topics were covered in earlier discussions. As mentioned earlier in this chapter, I believe that there was a positive impact of these earlier discussions, as they ensured that professionals had considered their responses to the questions asked. However, some might criticise this by suggesting that professionals could self- edit their responses. This criticism is predicated on the concept that a first answer is the most reflective of an opinion or perspective. In response to this, research has shown that serial or multiple interviews tend to enable a more reflective and comprehensive set of responses to set questions (Carter *et al.*, 2018).

Carer participants often preferred telephone interviews to Zoom interviews and completed a consent discussion in advance of the interview. Due to the delay in NHS research ethical committee approval, professional interviews commenced before carer interviews. The first phase of the data collection took place during the second national lockdown in England in 2021. It was a challenging environment in which to recruit busy and stressed NHS and social care professionals, who were often juggling short staffing situations, and high patient numbers. It was also a challenging environment for carers who were without respite, and many were unable to take part in interviews. The majority of carer interviews took place after the easing of social distancing measures in the summer of 2021, when carers were able to find respite in the community and had the ability to take part in research.

4.6.2 Recruitment

I recruited participants in very different ways across the two studies due to the different ethical approvals and regulations in place. I began recruiting health and social care professionals via my professional network and ultimately via the CRN (clinical research network). I began recruitment of participants by contacting professionals I had met via conferences and dementia policy groups. I connected with several different CRN groups who supported me to reach a wider pool of potential participants across different NHS Trusts in England.

The process of recruiting professionals remotely via email, news bulletin, and the NHS intranet, during a pandemic was challenging. Many professionals were time poor due to staff sickness, isolation policies, and burnout, following the many months of the pandemic. Organising a suitable time for an interview was tricky. I was, and I am, extremely grateful for the time the individuals in this research study gave me during a very difficult period in their professional lives.

Recruiting carer participants during the height of the pandemic proved at times almost impossible. In the qualitative research handbook, *Doing Qualitative Research* (Silverman, 2013, p. 216), there is a section detailing a PhD student's struggles to recruit participants in an international setting. This student faced a vast array of recruitment hurdles including local research councils, travel disruptions, and language barriers. Silverman's commentary is that this is a nightmare scenario that would be unlikely for the average PhD student. However, 2020 re-wrote the rule book on difficult participant recruitment environments. The ongoing uncertainty around travel and access, the UK lockdown hokey cokey, the profound impact on carers and other vulnerable groups of long-term isolation and lack of social support, alongside issues around burnout and sickness within the NHS, and social care sector created a hostile recruitment environment.

I began recruiting carers via voluntary community groups and Facebook posts. I also attempted to recruit participants via local council websites and newsletters. It was a difficult process as most carers were exhausted from the ongoing strain of the pandemic and the absence of respite and community support. I eventually connected with an Admiral Nurse based in the community who referred me to a network of carers who had experienced the hospital discharge process and were keen to be involved in the research project.

The recruitment process for carers involved a consent discussion being held separately to the interview to ensure that the participant understood what taking part in the research involved. When I reflect back on the recruitment process, there were a lot of false starts and hours spent speaking to individuals who ultimately decided not to be involved, or who could not aid me in recruitment further. It was a very labour intensive and grinding process for me as a novice researcher who was feeling fatigued and lacking in respite due to caring for a toddler during a pandemic. However, I recognise that my experience as a researcher reflects the experience of my participants, and of many people within the UK during the corona virus pandemic, when respite was withheld in the workplace and at home to limit the spread of the virus.

4.6.3 Sampling

I intended to utilise purposive (Coyne, 1997) sampling to identify individuals with the necessary experiences to provide rich, qualitative data. Due to pandemic conditions, I had to sample individuals who had the time, capacity, and interest in being involved in the research. I aimed to include a broad sample of carers that reflected the diversity naturally evident in the carer population. I did not specifically target male or female carers or any specific age group or experience range. In relation to health and social care professionals, I aimed to recruit a wide variety of roles and professions to ensure a full picture of the discharge process. However, the significant pressure that the NHS and social care system was under meant that I had to interview professionals who could find the time to speak to me in a very difficult working climate.

Carer participants included sons, daughters, daughters-in-law, spouses, a granddaughter, and a niece. I interviewed 14 carers and transcribed 13 hours and two minutes of data. 10 carers opted to take part via video interview, four carers chose to take part in a telephone interview. Table 8 includes the details of professional and carer participants. Table 9 contains further details regarding the length and reason behind the hospital stay. Please note that the name of each carer included has been anonymised to protect participant confidentiality. All carer participants were based in the UK and all professionals were working for the NHS, Local Authority or had significant experience of working within and with the NHS. The professional participants have been given a number to differentiate their input.

Table 8. Participant details regarding interviews.

Table 8				
Carer interviewee and location	**Relationship**	**Interview length and method**	**Professional Interviewee and location**	**Interview length and method**
Carol (Northwest)	Daughter in law	1 hour 12 mins Video (Zoom)	Nurse 01 (Northeast)	45 minutes Video (Zoom)
Louise (Northwest)	Volunteer and daughter	27 minutes Video (Zoom)	Specialist Dementia Nurse 4 (Southeast)	23 minutes Video (Teams)
Michael (Northeast)	Son	19 minutes Video (Zoom)	Specialist Dementia Nurse 3 (Southeast)	1 hour 5 minutes Video (Teams)
Shelly (Northeast)	Daughter	1 hour 11 mins Phone	Specialist Dementia Nurses 6 and 7 (Joint Interview)	1 hour 10 mins Video (Teams)
Katie (Northeast)	Daughter	1 hour 50 minutes Phone	Specialist Dementia Nurse 2 (Southeast)	32 minutes Video (Teams)
Elizabeth (Southeast)	Wife	55 minutes Video (Zoom)	Occupational Therapist 01 (Southeast)	29 minutes Video (Teams)
Harriet (Northeast)	Niece	1 hour 10 minutes Video (Zoom)	Physiotherapist 01 (Northeast)	37 minutes Video (Teams)
Jane (Northeast)	Granddaughter	1 hour 20 mins Video (Zoom)	Specialist Dementia Nurse 5 (Northeast)	33 minutes Video (Teams)
Abdul (Midlands)	Son	45 minutes Video (Zoom)	Social Worker 01 (Northeast)	35 minutes Video (Teams)

Faizal (Southeast)	Son	49 minutes Phone	Consultant 01 (Northeast)	43 mins Video (Teams)
Amy (Northeast)	Daughter	1 hour 16 minutes Phone		
James (Northeast)	Son	1 hour and 2 minutes Video (Zoom)		
Jack (Northwest)	Husband	1 hour 34 minutes Video (Zoom)		
Anne (Northeast)	Daughter	1 hour 15 mins Video (Zoom)		
Total		13 hours 02 minutes		6 hours and 58 minutes

Table 9. Information regarding hospital stay.

Table 9		
Carer	Length of Stay of person living with dementia	Reason for Hospitalisation
Carol	Two weeks	Infection
Louise	Multiple admissions	Unclear
Jack	Longer than three weeks	Urinary Tract Infection
Shelly	Multiple admissions	Multiple reasons including infections, falls, crisis in care
Katie	Multiple admissions	COVID 19/other chest infections and related complications
Michael	Multiple admissions	Crisis in care
Harriet	Longer than three weeks	Chest infection
James	Multiple admissions	Frailty, falls
Anne	Multiple admissions	Frailty
Jane	More than three weeks	Fall
Elizabeth	Multiple admissions	Frailty
Abdul	Multiple admissions	COVID 19
Amy	Two weeks	Frailty

Faizal	Multiple admissions	Unclear

4.6.4 The topic of the interviews

The semi-structured interviews included specific questions; the general focus of which participants were informed of via the participant information sheet (Included in Chapter 14). The pre-arranged questions were different for the carer group and the professional group, although both sets of questions focused on wellbeing during the hospital discharge process. I altered the questions to fit the interviewee's role or position, but the content of the questions was largely identical across the interviews. However, the range of responses was large.

Utilising a social constructionist lens meant that carer participants were encouraged to explore the aspects of wellbeing they felt were relevant to themselves and this led to a wide range of topics being discussed within the interviews. The decision to view the discharge process in its extended form led to carers focusing on different aspects of the process, from the day of discharge to the first days in the community post- discharge. While some carers focused on medication or transport, others focused on multi-disciplinary team meetings or documentation. This allowed carers to identify areas they felt were important to them as experts in the discharge process. Professional participant responses displayed more uniformity and less divergence. The impact of COVID 19 penetrated nearly all aspects of the discharge process and arose constantly in discussions due to the study period coinciding with the UK's second lockdown.

The questions aimed to adhere to the tenets of the Appreciative Inquiry model and focused on positive aspects of the experience that could be further developed (Bushe, 2007). Examples of this are: *What support (emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What went well during the discharge process? What support has helped you to maintain your physical and emotional well-being following your relative's hospital discharge?*

These questions aimed to identify positive and generative discussions within the interview (Priest *et al.*, 2013) in accordance with the Appreciative Inquiry approach. Furthermore, the open-ended questions allowed for individual experiences to be highlighted in cohesion with the social constructionist approach.

4.7 The analytic process

I considered several different analytic approaches including grounded theory (Charmaz, 2006) and applied thematic analysis (Guest, MacQueen and Namey, 2011). Grounded theory appealed due to its long-standing establishment within health and social care research and its focus on themes emerging from the field work and raw data (Glaser and Strauss, 1967). However, as previously discussed in this chapter, grounded theories focus on coming to the field with no prior knowledge and its rigid, structured research method did not align with my position as a nurse and researcher in the field, and therefore, my pre-existing knowledge and positionality (Mills, Bonner and Francis, 2006).

The decision to utilise the thematic analysis method occurred after a careful consideration of the benefits and drawbacks of this analytic method, and of others frequently adopted by researchers in qualitative health care research. Ultimately, I valued applied thematic analysis' ability to offer a transparency to the analytic process. This is ultimately important for judging the merit of the findings (Guest, MacQueen and Namey, 2011). I also appreciated the pragmatic approach of the method and its focus on an exploratory, case study format aimed at problem solving and moving beyond descriptive analysis to explanatory considerations (Braun and Clarke, 2013; Braun and Clarke, 2019). I combined thematic analysis with the Appreciative Inquiry method to enable the analysis to focus on the strengths of the discharge process where possible, what was working well, and what participants believed needed to improve. The Appreciative Inquiry process and thematic analysis have been combined successfully in previous research due to the inherent flexibility of the thematic analytic method, and its ability to work in conjunction with an Appreciative Inquiry approach (Watkins, Dewar and Kennedy, 2016).

Applied thematic analysis has a significant history within the context of healthcare research (Elliott and Gillie, 1998; Austin *et al.*, 2000; Goodridge *et al.*, 2005; Tuckett, 2005; Chapman, Hadfield and

Chapman, 2015; Karavadra *et al.*, 2020) and has many positive aspects for the pragmatic healthcare research process and researcher (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2014). Although only recently has it has been fully codified as an analytic method (Flick, 2006). Thematic analysis has been utilised in many important and significant research projects in the field of dementia (Butcher *et al.*, 2001; Leong, Madjar and Fiveash, 2001; Phinney, Chaudhury and O'Connor, 2007; Sun, 2014; Giebel *et al.*, 2020; Fekonja *et al.*, 2021) and hospital focused health practitioner research (Grob, Bläuer and Frei, 2017; Laur *et al.*, 2017). The key aim of thematic analysis is to identify themes which develop into codes and are structured upon 'implicit and explicit ideas in the data' (Guest, MacQueen and Namey, 2011, p.38). The method offers a flexible analytic approach which can incorporate different ontological and epistemological perspectives without being overly prescriptive.

However, the method has not been without its critics (Vaismoradi, Turunen and Bondas, 2013; Braun and Clarke, 2020). Thematic analysis has faced criticism for being ambiguous and for researcher analytic decisions and processes being unclear (Vaismoradi *et al.*, 2016). It is noted that this is a common criticism of qualitative analysis techniques generally that is not limited to applied thematic analysis (Choy, 2014). The justification of the criticism is debated within the theoretical scope of qualitative analysis as it is based on the standards and paradigm of quantitative research which is not applicable to qualitative ontology and methodology.

In response to these critiques, theorists (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2014) have developed flexible but transparent processes which have strengthened applied thematic analysis' ability to support robust analytic findings, and answer the criticisms raised. The development of these measures, which provide a structure and set of procedures to follow within the analysis process, means that whether the analysis process is robust or questionable is now related to the strength of the researcher and the quality of their application of thematic analysis, rather than the method itself.

The applied thematic analysis process aligns well with the context of the health service and is regularly used in this applied context. Healthcare service research is markedly different from other forms of sociological research as it is heavily influenced by the sphere of medical research. Medical research has a positivist outlook and identifies quantitative research as the pinnacle of the hierarchy of research methods. This relationship with medical research has broader implications for healthcare research theoretically and practically, in terms of how researchers develop and think about their research methodology, and how they implement it.

The emphasis on the development of a code book, for example, and the visible development of themes and codes aids the trustworthiness (Auerbach and Silverstein, 2003; Corbin and Strauss, 2008) and credibility (Lincoln and Guba, 1985) of the data, an important consideration in a field heavily aligned with medical research and quantitative methods. The emphasis on member checking and triangulation further supports the more positivistic style of the medical research field. Further to this, the systematic and transparent research process, with a focus on audit trails and clarity, aligns with the rigour of the NHS ethical approval process and the requirements for record keeping.

The inherent movement in the coding from description to analytic interpretation is important for a study hoping to aid decision making around policy, an objective of most research aligned to the field of healthcare. Applied thematic analysis’ ability to facilitate both inductive and deductive analysis (Guest, MacQueen and Namey, 2011, p. 37), and to allow structural coding alongside more iterative frameworks, is particularly useful in a context where answers to pragmatic questions are being sought, and rigorous ethical requirements dictate that questions should be known to participants in advance.

In relation to the scope of the research undertaken in this instance, the ‘exploratory’ (Guest, MacQueen and Namey, 2011, p. 7) nature of the thematic analytic process, alongside the focus on ‘solving practical problems’ (Guest, MacQueen and Namey, 2011, p. 10) and ‘complex social systems’ (Guest, MacQueen and Namey, 2011, p. 35), fits well with the objectives of the research project (Guest, MacQueen and Namey, 2011). It also aligns with the Appreciative Inquiry approach which specifically aims to address practical problems and identify solutions. Hospital discharge is a very complex, practical process located inside a multifaceted health and social care institution. Therefore, a process which can pragmatically accommodate this system is ideal. Thematic analysis explicitly allows for processes to be explored (Guest, MacQueen and Namey, 2011, p. 17), and this aligns with the nature of the project to explore the discharge process from different perspectives.

4.7.1 Impact of social constructionist approach on analysis

The social constructionist approach ensured that focus on individual experience, and understanding of the discharge process, was maintained during the analysis process (Blustein, Palladino Schultheiss and Flum, 2004). Instead of focusing on mechanisms or objective external factors, the social constructionist approach enabled a focus on the factors identified specifically by participants through their experiences. During the analysis process, this allowed for an understanding of the multiplicity of concepts, such as person-centred care. Further to this, it enabled an appreciation of the different perspectives of the discharge process held by health and social care professionals and carers.

4.7.2 Applied thematic analysis

In keeping with the tenets and process of thematic analysis, I began by open coding transcripts (Guest, MacQueen and Namey, 2011) using a computer assisted qualitative data analysis package, know as NVivo 12, to identify all emerging themes from the data. I paid close attention to the raw data from the interviews and everything of note was recorded in a ‘node’, within the parlance of NVivo. I coded transcripts as they were available and this allowed me to identify the themes emerging very early in the analysis process (Guest, MacQueen and Namey, 2011). I did not at this point progress to identifying codes as required by the applied thematic analysis method but instead divided segments of the interview transcripts into themes only. There were many diverse themes evident in professional and carer interviews. I chose to analyse carer and volunteer interviews separately to professional interviews. The themes identified within the systematic review and literature review, alerted me that it was probable that the perspectives of professionals and carers would be divergent and therefore, should be analysed separately. This involved reading the transcripts line by line, and creating a new node within NVivo that represented the topic emerging from the data or assigning the section of data to a delineated node within NVivo. This process was completed immediately after transcription was performed, often on the following day. Transcripts of professional interviews were analysed in a separate NVivo file to carer interview transcripts. There was significant duplication of themes at this early stage as aspects of the same theme were analysed individually. Consequently, there was a very high number of initial nodes (104 from professional transcripts and 149 from carer transcripts). NVivo coding examples are included in Chapter 14.

Having conducted the systematic review qualitative synthesis outlined in Chapter 2, I had insight into possible themes that might develop from carer interview data. I avoided explicitly revisiting the findings of the systematic review in detail before completing the initial analysis process. When reading the findings of the systematic review after immersing myself in the coding process, I was pleased to identify that there was correlation in findings. As expected, this excluded the impact of the pandemic. During this time, I composed a descriptive narrative to develop my understanding of the complexities and challenges of the discharge process, wellbeing and how COVID 19 appeared to be impacting on this.

This inductive coding process began to reveal the complexities and challenges of maintaining wellbeing during the discharge process, particularly during the pandemic period. The Appreciative Inquiry approach (Cooperrider and Fry, 2020) allowed me to explicitly focus on areas where the discharge process worked well, and what participants believed either was, or would, support wellbeing. This enabled the analysis to follow the strengths based and generative approach of the Appreciative Inquiry theory (Bushe, 2007). Discussions were held with my supervisors regarding the descriptive narrative text, the content of the data, and how to approach further analysis.

As I identified more and more themes, as I progressed through the transcripts, I began grouping them into dominant, multi themed nodes within NVivo and analysing which themes were emerging as codes in their own right. To achieve this, I looked at each individual node and whether the themes within worked cohesively together, and whether the individual themes were related closely enough to develop a comprehensive code. From this point, I began to develop the beginnings of a code book. Guided by the examples in Guest, MacQueen and Namey (2011), I outlined the content of the emerging codes and wrote a thick description of each code (Geertz, 1973). This process was iterative, and the boundaries of each code were not clear cut in the early phases of code book development.

I utilised the code book to code each subsequent interview, noting whether each theme fit into the code developed or not. The codes within the code book evolved during the subsequent coding process as the input of participants expanded my understanding of the hospital discharge process. The Appreciative Inquiry approach of focusing on the strengths of the process and on proactive ways to improve processes (in this case supporting wellbeing), was central to all analysis and influenced my coding decisions (Cooperrider and Whitney, 2005). Examples of this can be seen in the subthemes such as the Hope subthemes: *Health and social care professionals supporting self-actualisation for people living with dementia and their carers; and the impact of stress on preventing wellbeing, self-actualisation and maintaining hope during the discharge*. The emphasis of the analysis was to build upon that which was identified within the data as supporting wellbeing during the discharge process. Further detail regarding the theoretical concepts underpinning the code development is discussed in the next section of this chapter.

Once I had coded all interviews, I re-read a selection of the interviews with the coding book. This allowed me to assess whether the coding book truly reflected the content of the interviews. I found that the code book did reflect the content of the interviews. There were occasions during the writing up stage where I found repetition of data or not enough content to a particular code to justify its inclusion. When this occurred, I considered whether the content could be conflated with the content of another code.

4.7.3 Further detail of code book development and content of findings and themes

While I was exploring the initial codes generated from the data, I reflected on established academic theory regarding the nature of wellbeing, particularly in relation to people living with dementia and their carers. I returned to Kitwood and Bredin's theoretical writings about personhood for people living with dementia and the importance of wellbeing (Kitwood and Bredin, 1992). It was evident that the key tenets of the theory were identifiable in the data derived from both carers, and health and social care professionals, in relation to the discharge process.

Kitwood and Bredin (1992) identified four 'global sentient states' that could ensure wellbeing for people living with dementia; personal worth, agency, social confidence, and hope (Table 10 outlines this further). Social confidence immediately appeared less applicable to carers and the hospital discharge process in general and did not fit with the early codes emerging from the data. However, the other three areas identified as supporting wellbeing corresponded with the overarching themes emerging from the interview data. Applied thematic analysis (Guest, MacQueen, and Namey, 2011) allows for deductive, structural coding that can enable data to be analysed in concurrence with an established framework or theory. I began re-organising the descriptive themes, from both the carer and professional analyses, according to the tenets of Kitwood and Bredin's (1992) overarching theory of wellbeing. The substance of the themes from the analysis presented here are devised from my own inductive applied thematic analysis (Guest, MacQueen and Namey, 2011), only the overarching themes are derived from the theory of Kitwood and Bredin (1992).

Table 10. Definitions of Kitwood and Bredin's global sentient states of well-being.

Table 10	
Kitwood and Bredin's global sentient states of well-being	Definition. Please see: Kitwood and Bredin, 1992. *Towards a theory of dementia care: personhood and well-being, for further information*
Personal Worth	The deepest level of self- esteem.
Agency	The ability to control personal life in a meaningful way.
Social Confidence	The feeling of being at ease with others.

Hope	A freedom for anxiety if basic needs are met. A confidence that security will remain in a changing atmosphere. The sense that the future will be good.

Table 10 depicts the definitions of Kitwood and Bredin's global sentient states of wellbeing. I incorporated my own findings from the analysis of the data to expand on the detail of Kitwood and Bredin's theory of wellbeing (1992) and to explore how this definition can be understood and supported within the context of the discharge process. I created cases and case classifications within NVivo to facilitate the development of a codebook (Guest, MacQueen and Namey, 2011) (An example of this is included in Chapter 14). I also developed a code entitled Dream, in accordance with the Appreciative Inquiry approach (Coperrider and Whitney, 2011). This theme contains the opinions of carers, and health and social care professionals, concerning the areas of the discharge process that are perceived as requiring change. Furthermore, I ensured that the analytic process was focused not on solving problems, but on identifying strengths and potential solutions in accordance with the Appreciative Inquiry approach (Priest *et al.*, 2013). Developing the Dream code allowed me to explicitly utilise the Appreciative Inquiry cycle within the analysis process and draw out from the data the expert opinion of professionals and carers, of the changes required to ensure the maintenance of wellbeing for both carers and people living with dementia. Utilising the Appreciative Inquiry method enabled me to focus both interviews and the analysis process on what works well within the discharge process and what supports wellbeing (Bushe, 2007). This supported me to generate a model of the discharge process focused on supporting wellbeing at a later stage in the analytic process.

I drafted a descriptive, short summary of each of the overarching codes emerging from the data to support the code book in late November/early December 2021. The contents of each code are included in Table 11. Note that codes and themes are synonymous.

Table 11. Code descriptions.

Table 11	
Code	Code description
Personal Worth	This is about valuing and respecting the carer as an individual, alongside the person with dementia, within the hospital discharge process across both the hospital and the community context. Carer identity is conflated with the person with dementia and therefore, their needs must be considered and supported within the discharge process. Person-centred care must include the carer. This has been affected negatively by COVID 19. The importance of which is demonstrated when personal worth is not evident within the discharge process. Must ensure carer is capable of caring and has the training required. Professionals focused on person centred care but often not delivering it. 1. Ensuring inclusive person- centred care (care for the patient and good communication for carer) 2. Being treated as a care partner throughout the process, addressing the power imbalance? 3. COVID 19 impact on valuing the carer of a person living with dementia alongside the individual living with dementia (positive and negative)
Agency	This is about ensuring carers are able to be involved in decision making and that processes, people, and contexts enable that inclusion. Moving away from medicalised ideas regarding risk dominating decision making in relation to people living with dementia. 1. Processes that ensure carer involvement 2. Individuals that support carer empowerment (Professionals often undermine carer empowerment and admit this themselves) 3. Contexts that enable equality (and allow risk taking) 4. COVID 19 and the prevention of agency

Hope	This is a less tangible but vital aspect of wellbeing only achievable when basic needs are met. Respite, financial support and basic support to allow for social activity and hope for the carer and person with dementia. Impact of COVID 19 on this is significant, especially as it is causing uncertainty around community service availability and social contact for carers. Professionals are aware of the impact but not focused on this within the discharge process. Being aware of the impact of being a carer. 1. Moving beyond basic physical needs (Actualisation) 2. COVID 19 and uncertainty (preventing respite, mental health impact and discharge services availability, fear) 3. A supportive environment (finance for carers and carer/patient services)

Table 11 contains a description of the codes generated. Once the codes had been broadly established, I printed a list of the data assigned to each of the four codes and identified what was contained within each. This was a separate process for professional data and carer data. This allowed me to identify the detail of the broader codes in the two interview groups. Once I had identified the internal themes within the broader codes (Table 12), I spent further time looking at the minutiae of these internal themes, and how they would be expressed within the findings. I completed this process across carer and professional data to enable the comparison of these perspectives within each code. This allowed me to identify the differing concerns of the two interview participant groups. I identified the impact of COVID 19 regulations within each code to illuminate the significant impact of the pandemic on wellbeing. Once the internal structure of the codes was established, I wrote small summaries of each code and the internal levels of the themes. Within the four overarching themes of Agency, Personal Worth, Hope and Dream, nine further themes and twenty- six further subthemes were identified and summarized, before the write up of the findings began in earnest.

Table 12. Detail of individual themes.

Table 12	
Professional Themes	**Carer Themes**
Agency	**Agency**
1 Supportive health and social care professionals enabling empowerment	1 Supportive health and social care professionals enabling empowerment
2 Empowering processes	2 Empowering processes
3 Contexts that enable equality and risk taking	3 Contexts that enable equality and risk taking
4 COVID 19 and the prevention of agency	4 COVID 19 and the prevention of agency
Hope	**Hope**
1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)	1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
2 A supportive environment enabling the maintenance of hope	2 A supportive environment enabling the maintenance of hope
3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope	3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope
Personal Worth	**Personal Worth**
1 Ensuring person-centered care	1 Ensuring person-centered care
2 Being treated as a care partner	2 Being treated as a care partner
Dream	**Dream**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in relation to the availability of a social worker	Extensive explanation of the discharge process, including transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options

Additional care package availability in community, including additional support systems	Adequate signposting
Changes beneficial to the person living with dementia and their carer:	Further holistic involvement in the discharge process, including being given choices
Further focus on the wellbeing of carers and people living with dementia	Further respite availability factored into discharge process
Removal of stigma and discrimination from discharge process	Meaningful communication replacing platitudes and inclusion of communication tools
	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

Table 12 reveals the detail of individual themes**.** As stated earlier in this section, while Hope, Personal Worth and Agency are the overarching themes identified by the wellbeing theory proposed by Kitwood and Bredin (1992), the detail of the themes is derived from inductive analysis of the empirical data of this research study and expands this definition into this context.

4.7.4 Conclusion

In this chapter I have outlined the theoretical approach of this research project including the social constructionist ontology and the qualitative method emerging from this methodology. I have also detailed the interview method and some of the challenges of recruitment during the pandemic. Furthermore, I have discussed the Appreciative Inquiry method and how applied thematic analysis as utilised to analyse the data. In the next chapter, I will outline the findings of the analytical process.

Chapter 5. Outline of findings

5.1 Introduction

In previous chapters I have outlined the setting in which this research project took place, and the literature available in relation to the hospital discharge process and the experiences of carers and people living with dementia. This chapter and subsequent chapters detail the qualitative findings of the methods employed. The social constructionist (Berger and Luckmann, 1991) lens was applied to the analysis process alongside the Appreciative Inquiry method (Cooperrider and Whitney, 2005), and Applied Thematic Analysis (Guest, MacQueen and Namey, 2011). Detail of how the codes, code book and resulting overarching themes were developed is included in the previous chapter.

In the following chapters, I will outline the findings of my analysis. I interviewed twenty-five carers and health and social care professionals for this research project. Fourteen carers were interviewed, and thirteen hours and two minutes of data transcribed. Four carers took part in phone interviews and ten carers took part via video interview. The decision to define the hospital discharge process as one extended process meant that it was important to speak to a diverse group of health and social care professionals, including admiral nurses, medical staff, social workers and other allied health and social care professionals. I interviewed eleven health and social care professionals and transcribed six hours and fifty-eight minutes of interview data. All professionals opted to take part in the interview via video interview.

At this point I will re-state the research questions of this research project to demonstrate how the findings of the project addressed these questions: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

Table 13 outlines the individual themes of the four key overarching themes identified through the applied thematic analysis method (Guest, MacQueen and Namey, 2011) that reveal the facets of wellbeing during the discharge process for people living with dementia and their carers. Informal carers and care professionals identified that ensuring Agency, Personal Worth and Hope was crucial to both defining and safeguarding the wellbeing of both carers and people living with dementia during the leaving hospital process.

In response to the secondary aim of developing the definition of wellbeing in this context. The deductive thematic analysis process generated the following definition of wellbeing: *wellbeing during the discharge process is the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond*. The detail of what is meant by ‘agency, hope and personal worth’ is included in the findings of the analysis presented within the separate chapters.

The concepts of ‘agency, hope and personal worth’ derive from Kitwood and Bredin (1992) and their theory of wellbeing, but there is little content to these concepts, and they are not reflective of specific contexts. The definition provided here is specific to the discharge process. In this definition the detail is included in the themes and subthemes. Agency is comprised of *empowering processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*.

Within the overarching themes of Hope, Agency and Personal Worth the factors that support the maintenance of wellbeing for this patient and carer dyad are revealed. The themes are delineated in table 13.

Table 13. Themes.

Table 13	
Professional Themes	**Carer Themes**
Agency	**Agency**
1 Supportive health and social care professionals enabling empowerment	1 Supportive health and social care professionals enabling empowerment

2 Empowering processes	2 Empowering processes
3 Contexts that enable equality and risk taking	3 Contexts that enable equality and risk taking
4 COVID 19 and the prevention of agency	4 COVID 19 and the prevention of agency
Hope	**Hope**
1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)	1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
2 A supportive environment enabling the maintenance of hope	2 A supportive environment enabling the maintenance of hope
3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope	3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope
Personal Worth	**Personal Worth**
1 Ensuring person-centered care	1 Ensuring person-centered care
2 Being treated as a care partner	2 Being treated as a care partner
Dream	**Dream**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in relation to the availability of a social worker	Extensive explanation of the discharge process, including transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options
Additional care package availability in community, including additional support systems	Adequate signposting
Changes beneficial to the person living with dementia and their carer:	Further holistic involvement in the discharge process, including being given choices

Further focus on the wellbeing of carers and people living with dementia	Further respite availability factored into discharge process
Removal of stigma and discrimination from discharge process	Meaningful communication replacing platitudes and inclusion of communication tools
	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

It is important to acknowledge that the overarching themes of Hope, Agency and Personal Worth remain subjective terms even when supported by the definition provided by Kitwood and Bredin (1992). However, this subjectivity aligns with the broader social constructionist epistemology of this research project. Agency will not appear identical across different carer experiences. While it is important to clearly define the term, it should also be accepted as having multiple applications and meanings for participants.

Before exploring the content of the themes in individual chapters, three carer narratives will be outlined to highlight the diversity of the care experience and each carers' circumstances. These three carers were specifically chosen to acknowledge the importance of individual experience. Throughout the chapter the differing experiences of carers are highlighted to platform the individuality, and multiplicity of terms such as hope. The individual experiences of Jack, Michael and Katie, are outlined here to contextualise the findings of this chapter within the lived reality of the carer.

5.1.1 Jack

Jack is a carer for his wife who has a diagnosis of dementia.

Jack had a very poor experience of the hospital discharge process. Jack did not feel involved in the process or fully informed or involved in decision making. His wife appeared at home in the middle of the afternoon, in a wheelchair, in a hospital gown, with a blanket, on their doorstep. This annoyed Jack, who was not given warning of the discharge time and could have been out of the house.

Jack receives excellent support from an admiral nurse but found communication with the hospital difficult. Jack has limited community support financially or socially from family and friends. Jack found individuals very helpful but felt that the processes of discharge must be improved.

COVID 19 prevented Jack from visiting his wife on the ward. Jack's wife's condition declined significantly during her hospital stay and technology was of limited use. Jack felt that the care received by his wife in hospital did not address her needs as a person living with dementia. Jack found the NHS systems confusing, and the care landscape perplexing in the aftermath of the discharge. He believes that there is limited help available to carers. Jack also discussed how the presence of PPE impacted negatively on his wife's care and her ability to communicate with health and social care staff.

5.1.2 Michael

Both of Michael's parents were discharged from hospital to a care home at the same time. Both had a diagnosis of dementia.

Michael had a good experience of the hospital discharge in relation to communication with hospital-based professionals. He experienced both phone calls and a face-to-face discharge meeting, in a pre-COVID era, which were attended by professionals on the ward, and organised by a professional at the hospital (discharge co-ordinator). Michael felt that the discharge went well, and that the availability of hospital transport enabled a smooth transition to the care home.

Michael received excellent support practically and emotionally, from a community-based admiral nurse employed by a charity. He found the process of finding a care home quickly quite difficult, and emotionally very problematic, and has a lot of guilt connected to the process.

The admiral nurse helped somewhat with this feeling, but the guilt is still present. Michael has had no support from social services and has no support in the community. Michael found the caring role very difficult, and it became impossible to manage alongside his career. He believes there should be more support for carers, particularly around financial entitlements, and support services available (if there are any). Michael believes that you are left to get on with the practical and financial measures alone as a carer.

5.1.3 Katie

Katie cares for her dad who has dementia.

Katie had a poor experience of the hospital discharge process overall, with limited communication from the hospital across her dad's multiple discharge experiences. Katie had to repeatedly ring the ward and ask for information and did not feel involved in decision making around discharge despite having power of attorney. Katie was not contacted or communicated with regularly and important information was not passed on. No discharge plan or care plan was apparent at discharge. A kind ward sister compassionately enabled visiting once during the COVID 19 pandemic. Katie experienced many difficulties caused by the absence of ward visiting availability.

Katie was not supplied with relevant medication at discharge and believed that the discharge process was poor prior to COVID 19. Her dad admitted to hospital with COVID 19 following accidently taking GTN (Glyceryl trinitrate) spray in isolation, due to COVID 19 lockdown measures. He was discharged to a care home for emergency respite care and following implementation of a deprivation of liberty order (DOLS), a decision Katie was not involved in, social services quickly decided, after a delay caused by a COVID 19 backlog of work, that Katie's dad should be made a permanent resident.

She believed that her dad was assessed too soon after leaving hospital with COVID 19 having been on a CPAP mask. Katie did not receive advanced notice of the discharge or a discharge letter, and there have been issues with her dad's inhaler following discharge. The care home has refused to administer his inhaler more frequently. This has led to multiple hospital admissions.

Katie has fought to have her dad moved to a more appropriate care home, after her dad was very unhappy in the previous care home. The social worker undermined Katie's input and would only approve a move to another care home after a meeting in a car park, with Katie's dad, and a separate meeting with the care home manager.

The limited visiting available during the pandemic, based on government guidance, has been very distressing to Katie and her dad. Being unable to help her dad or see him has been detrimental to them both.

In the following chapters, l will detail the content of the findings of the analysis regarding the four overarching themes of; Hope, Personal Worth, Agency and Dream. Firstly, the theme of Hope shall be explored, followed by Personal Worth, Agency and Dream

Chapter 6. Hope

6.1 Hope

It was evident from the analysis that the ability to maintain hope during the hospital discharge process was central to maintaining the wellbeing of people living with dementia and their carers.

Within the concept of wellbeing, the sustainability of hope is a difficult concept to succinctly summarise, beyond the definition offered by Kitwood and Bredin (1992), due to its intangibility. However, it emerged within interviews as vital to protecting the wellbeing of carers and people living with dementia.

It was often easier to identify the absence of hope, due to the presence of despair, within carer narratives. However, the Appreciative Inquiry approach enabled a focus on ways of supporting wellbeing within the discharge process (Priest *et al.*, 2013). Therefore, the analysis inverted this finding to identify what prevented despair and what factors enabled hope. The identification of the absence of hope is an important finding as it magnifies the importance of hope within the Appreciative Inquiry analysis.

Being able to maintain hope for people living with dementia and their carers appeared to be supported by two main tenets; the ability of the discharge process to consider more than purely physical needs and logistics, and the availability of a supportive environment, both socially and financially, that allowed self-actualisation for both the person living with dementia and their carer.

This section of the analysis draws on Maslow's (Maslow and Lewis, 1987) theory of the hierarchy of needs and the concept of self-actualisation. Maslow suggests that human beings have a hierarchy of needs starting with basic physiological needs and moving through the levels of safety, love and belonging, and esteem, to the highest level of self-actualisation. Maslow defines this as being the most one can be when all other lower needs are fulfilled.

A significant portion of the analysis of the data from both professionals and carers, reflected how the integral uncertainty caused by the pandemic had a negative impact on the ability of people living with dementia and their carers to maintain hope, and prevented movement through Maslow’s hierarchy of needs. Fear, isolation in the hospital context, and limited community service availability, made the maintenance of hope difficult during the discharge process. Uncertainty around discharge options complicated decision making, and limited social contact led to patients deteriorating in hospital. Carers revealed the significant stress that uncertainty caused by the pandemic created.

Table 14 reveals the main subthemes that emerged in relation to the importance of hope for maintaining the wellbeing of carers and people living with dementia. The Impact of the Appreciative Inquiry approach in identifying potential strengths, and ways to improve the process is evident within the subthemes. The social constructionist emphasis on valuing individual insight is also evident.

Table 14. Hope. Themes and subthemes.

Table 14
Theme 1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
Subtheme 1.1 Health and Social Care Professionals supporting self-actualisation for people living with dementia and their carers
Subtheme 1.2 The impact of stress on preventing wellbeing, self-actualisation and maintaining hope during the discharge process
Subtheme 1.3 Carer insights into how to maintain hope and move towards the actualisation of wellbeing for both carers and people living with dementia
Theme 2 A supportive environment enabling the maintenance of hope
Subtheme 2.1 Ensuring adequate finances and services for carers
Theme 3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope
Subtheme 3.1 Pandemic related fear

Subtheme 2 Isolation in the hospital context caused by pandemic regulations
Subtheme 3 Limited-service Provision

Table 14 outlines the themes and subthemes of this concept. The first theme to be considered is the importance of being able to move towards self-actualisation, and away from purely physical considerations during the discharge process. This theme details some of the ways in which the ability to maintain hope can be prevented during the discharge process. This is important to note even in an Appreciative Inquiry project as theorists such as Reed (2007) identify that all findings must be presented to increase validity and transparency within the research process. I will begin by considering how health and social care professionals acknowledged that being aware of the necessity to support needs, beyond physical requirements, can help to support a movement towards self-actualisation for people living with dementia and their carers. Due to carers having greater insight into the importance of maintaining hope, their views are centralised within this chapter. The analysis of professional data and carer data is presented together in order to compare and contrast findings.

6.2 The importance of self- actualisation for maintaining hope (Moving beyond physical requirements)

6.2.1 Health and social care professionals supporting self-actualisation for people living with dementia and their carers

The analysis showed that the intangible need to maintain hope, and the indeterminate but vital factors that allow for self-actualisation, were rarely mentioned during interviews by most of the professional participants in comparison to carer data. However, some professionals displayed a significant understanding of the importance of moving beyond considering only the physical requirements of the discharge process and reinforced a movement towards helping to support self- actualisation for people living with dementia and their carers.

> *Occupational Therapist: I think you're looking at the here and now. How the client is feeling in the here and now. Make sure it's as positive an experience as possible. Valuing their thoughts or valuing their feelings, validating their thoughts and feelings as well. Even if they don't necessarily make a lot of sense, the feelings still need to be validated and taken into consideration. But I think then it's also looking for the future, its giving people hope, it's giving people a sense that there is a future to be enjoyed and yeah, and life is good'.*

Specialist dementia nurses displayed a sincere and thoughtful understanding of the emotional impact of the discharge process for the person living with dementia, particularly if the discharge destination is a care facility.

> *Specialist Dementia Nurse 3: Sad and angry, there'll be lots of emotions about it. Somebody decided you're not capable of going home. That it is better for you go somewhere else, you don't get a choice in where you go, because your family choose that for you. And you just end up sort of being taken to a room, with a few things that somebody else has chosen for you and that's it for the rest of your life and actually your property's probably being sold to fund that.*

The importance of explicitly acknowledging the need to maintain a sense of hope for the future to ensure wellbeing was discussed by some professionals within the interview context. However, the acknowledgement of the thoughts, feelings, emotions, and non-physical aspects of care for the person living with dementia and their carer, was not a common occurrence within the professional data.

Health and social care professionals that did have significant insight into the emotional difficulties of the discharge process, also had an awareness of the challenge's integral in the process for both groups. Anger experienced by people living with dementia over the loss of control regarding where they can live, and their lack of closure if they cannot return to their own home, was identified as preventing the maintenance of hope.

This highlighted the significant impact that discharge destination plays in relation to being able to sustain hope during the process. The Appreciative Inquiry approach allowed for the identification of the importance of ensuring an appropriate discharge destination environment, which is welcoming from both an emotional and comfort standpoint. One participant identified that making sure that the discharge destination was appropriately prepared for the person living with dementia was central to this. The requirement for awareness of the needs, beyond care packages and physical care assistance, that support individual wellbeing and the maintenance of hope was acknowledged. Specialist nurses identified the importance of ensuring that people with dementia feel supported and cared for. In relation to carers, the importance of being able to express their emotional condition, and find support beyond practical assistance, was evident for maintaining hope.

> *Occupational Therapist: We need to get this equipment in before, we don't want the client coming home before we've done all of this because it will be unsafe, or it will be in too much of a muddle that it wouldn't be good for the client. We want it so that, so once their home, they can just relax and all the changes have been made and the environment is as it should be, rather than having to make more changes once they get back home.*
>
> *Specialist dementia nurse 3: They are mentally in the best place possible, so, although they're in a hospital ward or hospital bed, which is not nice, that they feel supported and cared for, and that people are acting in their best interest and doing the best to get them moved on, as quickly as possible.*

Interestingly, the limited discussion amongst professional participants in relation to the maintenance of hope was commented upon by one participant, who felt that this aspect of wellbeing is not directly addressed by health and social care professionals in practice. The participant believed that this is due to the demands of their professional roles, which call for focus on other more tangible parts of the discharge process. It was identified that this results in less perceptible aspects of wellbeing, which are not related to physical needs, being overlooked.

> *Social Worker: I think that, for wellbeing, I think it's just, it's, it's looking at that person holistically, isn't it? And making sure that every aspect of their needs are met and if, you know, if somebody is unhappy and they're expressing, you know, that they feel that a need isn't being met and we need to respond to that instead of, 'cause, I think sometimes professionals can be a bit blinkered because of the pressures of work and the through put.*

That many of the professionals did not focus on the emotive aspects of the process, but instead on objective realities and practical discharge processes, stands in contrast to the much more emotionally focused carer perspective. In the next section, I will consider how the presence of stress prevented the maintenance of hope and self-actualisation for the carer during the hospital discharge process.

6.2.2 The impact of stress on preventing wellbeing, self-actualisation and the maintenance of hope during the discharge process.

The significantly stressful nature of the discharge process was discussed by nearly all the carer participants. Some carers experienced a sense of respite while awaiting their relative's hospital discharge due to being relieved of their daily caring role. However, many carers found it exceptionally stressful attempting to be involved planning and organising a successful discharge process.

> *Abdul: I think the experience is quite emotional and relief, so you kind of, I'm a carer you see for my mom and when she's in hospital, it gives me a sense of break, because I think at least she's there with the right staff and support. Obviously, you still have the anxiety and you think maybe she's not happy with the hospital food and I will take some food for her, I need to visit, she might get lonely. She might need company, but at the same time you kind of feel like it's so nice just not having to have to think about somebody all day.*

Carers referenced the impact that being a carer had on their lives and some of the negative consequences of the role outside of the discharge process. Carers discussed the day-to-day stress and uncertainty linked to being a carer, the loss of identity and fundamental life changes the role could cause, as well as the wider impact on the family dynamic and poverty from the loss of employment. All of these elements could make maintaining hope difficult for the carer during the hospital discharge process.

> *Katie: It just [adequate support] doesn't exist, and I found that out and I was working full time up until last year and it was because of dad, I had to give up my job because I literally couldn't*

> *stand the stress of it anymore, and I didn't want to go on the sick, and I had worked 38 years.*

These personal factors caused by becoming a carer played a significant role in the hospital discharge process as they represent the context in which decisions are made. Within the discharge procedure, the organisational process could be very demanding for the carer. Carers discussed how difficult and exhausting the endless phone calls to enable discharge decisions and arrangements could be, and the challenge this presented to maintaining their wellbeing and a sense of hope for the future.

> *Jane: There's probably stuff went on in the background that I've no idea about, so maybe I'm running them down a bit. But yeah, we did everything* ***. It felt like we did everything*** *.*

The pressure linked to fluctuations around changing plans, particularly on the day of discharge itself, were difficult for carers to adjust to. The sometimes-devastating emotional impact of the process, and its effect on wellbeing and the maintenance of hope were discussed. Jack in particular mentioned attempts not to cry on the day of discharge itself. Interactions with health and social care professionals could make maintaining wellbeing challenging, with carers describing being subjected to projected guilt linked to decision making around the discharge.

> *Jack: Yeah, so, so, my wife was in a terrible state. I nearly burst into tears, you know, I was quite shocked when I saw her. It was like, she's like I envisaged her to be in about four- or five-years' time.*

Maintaining a sense of hope during a care home destination discharge for the person with dementia was particularly challenging. Carers described struggling to cope with the shock and guilt of the decision, even when it was the right decision for the carer and person living with dementia.

> *Michael: I think, you know, you have these feelings of guilt, when you, when they go into a home, And I've been through that as well and it's, it's,* ***just not a pleasant experience*** *.*

The financial complications that accompany a care home placement made this process particularly challenging. James discussed the potential financial impact of the cost of funding a care home placement, the potential to lose his home in the future and the impact that had in relation to his ability to maintain a sense of hope and wellbeing. Another source of tension came from carers having to explain to their relative that they required a care placement, and the inevitable conflict if the person with dementia wanted to return home. Jane discussed her fears that her grandfather would fight a care home placement, even though he lacked the capacity to make independent decisions. Further to this, carers worried about the emotional impact of the transfer to a care home for their relative. The image of his mother on her own, in an empty room, in an unknown care home, was very distressing to James. Harriet summed up the symbolic difficulty of the decision to sell a property to fund a placement and the challenge such an action presented to the maintenance of hope.

> *Harriet: the thought of his bungalow gone, you know. That, it was all going to be really difficult. But it took a good while to find a care home place.*

However, whilst the stressful nature of the discharge process could make maintaining hope difficult, carers had excellent insights into ways to maintain hope during the discharge process. In accordance with the Appreciative Inquiry focus on vital and positive areas to build upon within a process (Scerri, Innes and Scerri, 2019), I will outline these insights in the next section.

6.2.3 Carer insights into how to maintain hope and move towards maintaining wellbeing for both carers and people living with dementia during the discharge process.

Carers had significant insight into ways to maintain hope and enable movement towards the actualisation of wellbeing during the discharge process. For people living with dementia, carers felt that taking care of little things to ensure their comfort was important. Enabling the person with dementia to choose to continue activities they enjoyed post-discharge, even if there was some risk attached, was felt to be vital to maintaining a sense of hope during the discharge process. Further to this, valuing and not objectifying the person with dementia was identified as integral.

> *Harriet: It was something I just had to make a trade off in my head about that, do I stop him drinking alcohol completely? I just decided to bear, whatever risks were involved with his drinking because he was getting so much enjoyment and social interaction out of it.*

Carers mentioned that discharge planning should aim to empower people living with dementia in a way that recognised their mental health and encouraged their abilities. One example of this was recognising the value of organising social activities to commence in the community, such as attending a day centre or music group. Carers also described ways in which they felt supporting the personhood of the individual living with dementia was vital to maintaining a sense of hope during the discharge process. Story telling such as this revealed generative ways that the discharge process could be improved, as has previously been identified in the work of Havens, Wood and Leeman (2006).

> *Louise: To me, the power of music is, is, is, the ultimate thing with, with, anybody, and especially with people with dementia. They come in, so a lot of the time with their shoulders down and they sort of amble to the table, and they sit down and then they go out and they're tall, or they're walking taller, and they've got a smile on their face and they absolutely love it. And they get a coffee and a biscuit while they're there and yeah, it's generally good fun yeah*
>
> .

For carers themselves, knowing that respite would be available as part of the discharge package, and that this would allow them time to pursue social activities and hobbies was vital to maintaining hope. A key element emerging from the analysis for maintaining a sense of hope was ensuring that the discharge process factored in carers having an element of freedom within their lives. This sense of freedom was often depicted in narratives as fleeting but vital.

> *Elizabeth: Early on, that when the carers came for their first visit of the day, which was the longest one to wash and dress him. I*

> *mean, I did my husband’s breakfast first thing and then the carers would arrive to wash and dress him so that was in theory, that was an hour's visit. And so, I would go out for a walk every day and get myself a coffee while they were doing that. So, I just knew, whatever else happened the rest of the day at least, you know, I'd been out.*

Further to this, carers and health and social care professionals identified a supportive environment as essential to maintaining a sense of hope throughout the process. This shall be explored further in the next section.

6.3 A supportive environment enabling the maintenance of hope: Finances and services for carers.

Health and social care professional’s recognised that the availability of a supportive financial and service environment during the discharge process was necessary for maintaining hope for carers and people living with dementia. Adequate and predictable finances, and the availability of services in the community was identified as fundamental by both professionals and carers to the maintenance of hope. Similarly, carers had a detailed insight into the impact of an inadequate environment and the harrowing impact of this on their wellbeing.

> *Shelly: I mean, I was probably about 8 stone when this all happened and I’m six stone now. I literally forgot to eat. I never went to the hairdressers, never went anywhere because I couldn't afford it, because I had no money.*

The value of service provision was understood and illustrated by both professionals and carers, and the impact of unavailable services during the pandemic was lamented by professionals.

> *Specialist dementia nurse 3: And I think that especially as lockdown’s been going on, a lot of families have been under pressure 'cause they have been not provided that support, as multiple teams are being closed and voluntary sectors haven't been able to go in.*

The analysis revealed that carers almost universally grieved the limited support available in the community, and the limited signposting offered by health and social care professionals. This led to carers feeling extremely challenged due to the absence of required services. Many carers expressed their puzzlement that basic signposting did not occur. Multiple carers identified that potential support options in the community were not signposted during the opportunity of the discharge process, nor was adequate support offered from the hospital. Carers also discussed how attempts to seek support were rebuffed by professionals in the community, who instead suggested it was the hospital's responsibility to address carer concerns. This left carers unsure where to turn for support. In contrast, health and social care professional participants generally did not address the limitations of the support or services available to carers, nor their impact on carer life and wellbeing, with any frequency or in any depth.

> *Interviewer: And did anybody kind of offer you any support?*
>
> *Jane: [Starts laughing] No! Is that a joke? [laughing] No is the short answer? Uhm, I don't know whether I can give you a longer answer. Certainly not me and not mom either.*
>
> *……from the hospital level and from when all this happened and a discharge point of view, absolutely nothing at all.*

The Appreciative Inquiry approach allows for a focus upon services and professionals who represent strengths within the current process. Admiral nurses were highly valued for the support they offered during the discharge process. Admiral nurses were identified as a particular asset within the process due to their supportive nature and role. Outside of admiral nurses and dementia charities, carers were reliant on Google to answer their queries, much to their surprise and dissatisfaction. Even charity support was identified as being of limited utility at times. Social services were accused of offering little to no provision and of making accessing any type of support difficult. This was due to the bureaucracy of the social care system and financial cutbacks leading to limited funding availability.

> *Michael: Well, you know, without the admiral nurse to be honest, I wouldn't have, he was advising all the way through. To be frank, there was nothing from social services really.*

Instead of offering help and guidance, social services were reluctant to share details regarding available services. This led to distress for carers and people living with dementia. The omission of advice or provision of respite services was identified as a particular problem for carers, as it prevented advance care planning. One carer identified that due to the lack of support available in the community, they had to pay for a private carer and were denied help and support by social services. However, some carers did receive support from the social care sector in relation to respite and wellbeing. This financial support was greatly appreciated by carers. In accordance with the Appreciative Inquiry approach, this highlights the importance and strength of having a supportive financial and service context, in enabling people living with dementia, and their carers, to maintain a sense of hope.

> *Shelly: But what social services should have told me was she could have got a place in a bungalow for dementia. Beside the *****, totally designed for dementia care, and social services, never told me that, they never offered any respite or any funding.*
>
> *Shelly: The only thing I got was, 'oh there's an emergency bed'. I didn't want an emergency bed, I wanted to be able to plan. When I wanted mum looked after, where I wanted her to go because I wanted to look at how the budget, so I could be in charge of what I was paying for.*

The biggest concern of carers, identified within the analysis, was the absence of financial support available, and the absence of guidance to help carers manage their finances. The complicated and convoluted nature of the assessments required to access financial support were identified as a significant barrier to accessing financial aid for carers. They were also depicted as difficult to complete during the discharge process. The fear and stress caused by the financial implications of care home costs on property and income were discussed. The opaque nature of the charges and costs of care packages were also criticised.

> *Elizabeth: The only real issue I ever had, which is now resolved was….. As you know, social care is means tested, our local authority didn't have, they didn't seem to have the operating infrastructure in place to actually produce appropriate invoices. I mean, I wasn't saying I don't think we shouldn't be paying, we should...I, with power of attorney, I didn't feel I should be paying*

> *for something, unless I had a piece of paper telling me what it was for.*

The lack of clarity around financial matters, and limited services, was acknowledged as being exacerbated by the pandemic. This shall be further discussed in the following section. It is important to detail negative experiences within the Appreciative Inquiry approach as it can highlight areas that be developed and avoids the criticism that Appreciative Inquiry ignores negative experiences (Trajkovski, Schmied, Vickers and Jackson, 2013).

6.4 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope.

A significant portion of the data reflected how the integral uncertainty caused by the pandemic impacted negatively on the ability of people with dementia, and their carers, to maintain a sense of hope. Fear, isolation in the community, and limited community services made maintaining a sense of hope difficult for carers, and people living with dementia, during the hospital discharge process. Uncertainty around discharge options, complicated decision making, and limited social contact, led to patients deteriorating in hospital, and carers experiencing very high levels of stress.

Professionals had a significant insight into how the pandemic caused uncertainty within the discharge process. Carers displayed a profound individual understanding of the pandemic's ability to prevent hope, but tended to generalise how the pandemic was preventing hope generally, rather than in relation to the discharge process specifically. The pandemic and its associated regulations, impacted on every aspect of the carer and person living with dementia's daily existence. This made it difficult for carers to disassociate the impact on the discharge process from the generalised impact.

Due to professional participants being able to articulate a clearer vision of the impact of the COVID 19 pandemic on the ability of people living with dementia and their carers to maintain hope within the hospital discharge process, the professional data shaped the final structure of the findings presented. Carer data aligned with the professional perspective and is highlighted throughout. This finding is in opposition to many of the other findings in this thesis in relation to other areas of wellbeing.

The analysis of the data revealed three key elements causing uncertainty within the discharge process and preventing carers and people living with dementia from maintaining a sense of hope and wellbeing. These were: fear of the virus; the impact of isolation in the hospital context caused by COVID 19 regulations; and limited-service provision in the community.

6.4.1 Pandemic related fear.

Fear of the pandemic contributed significantly to the presence of uncertainty within the discharge process. The analysis revealed that professionals believed that fear of catching COVID 19 prevented carers making decisions that were in the best interests of the person living with dementia. An example of this was carers opting not to visit their relative in hospital to help prepare for the discharge, when visiting was available to them, to the ultimate detriment of the person living with dementia and the carer themselves.

> *Specialist dementia nurse 2: But what's happened, of course, is that people are fearful, and so they choose not to come in because of the high risk, and so they are made very aware of the risks. And then I think, they think, wait a minute. If I'm old and vulnerable as well, coming in could put me at risk, so they definitely saw a huge downturn in the number of visitors. And so, the impact that has is, and I see it a lot, where the therapy staff are struggling with somebody to get them home, with following tasks, you know, being involved in adls [activities of daily living] things, moving and handling or whatever it is and always say, actually with the wife or the husband or the person that person feels most comfortable with, is here, that has an impact.*

It was manifest from the analysis that the media's portrayal of the pandemic was having a detrimental impact on carer decision making and creating a reluctance to visit acute settings. It was evident that this was impacting on the ability of professionals to build relationships with carers and plan the discharge process appropriately. This fear was articulated by carers themselves, including a reluctance by people living with dementia to enter the hospital. Carers were able to coherently discuss their fear, and even terror of COVID 19 in relation to themselves, but primarily discussed their concerns for the potential impact on the person living with dementia.

> *Abdul: At the last minute, they wanted to admit her to hospital, and she was frightened of all the stories about people going in and not coming out. And she refused to go in, the patients is like, I'm not going in because there's no chance they're going to send me back home alive. That was kind of a myth that the media has portrayed.*

Professionals identified that carers were reluctant to have domiciliary care workers enter their relatives' homes and were keen for hospitals to quickly discharge people living with dementia. This led to fears around catching COVID 19 being prioritised above the need to make the best discharge decisions possible for the person living with dementia.

> *Nurse 1: One patient we have now, we think she's going to need care at home but the family are dead against it until she has the COVID vaccine. And she's 101. But the son is very clear, we don't want any external carers until she's had the vaccine.*

Similarly, professionals noticed a reluctance on the part of carers to accept the person with dementia back home following hospital admission. Carers discussed how this reluctance to organise a home discharge stemmed from fears of catching COVID 19 and fears that their relative had deteriorated during the hospital admission. There was also anxiety expressed regarding being 'locked in the house' for long periods of time during lockdowns. Similar fears led to carers being reluctant to consider care homes as discharge destinations, due to the inability to visit individuals within care homes, and the incidence of COVID 19 within the care home setting. This reluctance led to conflict between professionals aiming to support the needs of people living with dementia and carers reluctant to expose their relatives to the perceived risks of care home admission.

> *Specialist Dementia Nurse 4: The isolation from COVID for patient's carers has meant there's a real reluctance for people to have people back from hospital. Whereas before people would have*

> *had people back, I think the thought of being locked in your house with somebody, maybe for another three or six months, is too much for some people to comprehend.*

The analysis showed that care home admission was the source of much strife for carers due to inherent uncertainty within the process. Changing rules around PCR (Polymerase chain reaction) tests and isolation periods, made an onerous and uncertain situation more difficult. Carers were separated from their relative by a scarcity of availability to visit both in the acute setting, and when their relative was discharged, and consequently did not know whether adequate discharge plans were in place. Further to this, carers felt acute distress from the extended separation periods. They often reported feeling that they were struggling with uncertainty in relation to what was allowed, including being physically present on wards and being involved in discharge meetings. Carers expressed a sense of powerlessness caused by fear of COVID 19, and also by the changing regulations which made certainty and hope difficult to achieve during the discharge process. This was particularly true for people living with dementia who were exposed to multiple and frequent isolation requirements on leaving the hospital setting, even with a negative PCR result. It was evident from the analysis that maintaining hope and wellbeing was an exasperating challenge for carers during the pandemic, particularly in relation to isolation requirements.

> *Katie: It was, it just kind of felt like dad went into hospital with COVID, he was treated for the COVID, he wasn’t treated for the Alzheimer’s or supported with the Alzheimer’s. I couldn’t get in [to the hospital], the dementia specialist staff couldn’t get in and he was discharged without any sort of plan in place. And it's always to do with, it's the dementia side of it just gets completely forgotten about. They don’t treat or support any of that for their wellbeing. They should try and keep them as, as, rehabilitated, as they were prior to their admission.*

6.4.2 Isolation in the hospital context caused by pandemic regulations.

It was evident from the analysis that the changing regulations of the pandemic, the potential for further lockdowns, limited social opportunities, enduring isolation, and ambiguity around what was permissible in the acute setting, created continuing uncertainty within the discharge process. In the acute setting, professionals identified that there was significant doubt around how to care for people living with dementia on the hospital wards. Accepted good practice regarding care for people living with dementia in the hospital setting was at times unavailable, due to uncertainty around COVID 19 regulations and social distancing. Group activities to promote socialisation were prevented. Professionals identified that people living with dementia lost tactile care vital to their wellbeing due to pandemic regulations and isolation guidelines. Professionals identified that technology could not replace the needs of people living with dementia in ways that were possible for individuals living without dementia. Technology replacing face- to- face contact was identified as particularly detrimental with a specific negative impact on privacy and dignity.

> *Specialist Dementia Nurse 3: I mean there's the loss of touch. You know, people want to be close to their relatives, they want to see them in person, they, you know, they want to be able to hold hands and things like that. You know, all of those, they can't be translated into a virtual contact, can they? Or if you want to give someone a hug, you can. Or make somebody a cup of tea and hold their hand. None of those things really can happen if you're on an iPad, can they.*

Isolation and limited-service provision in the acute setting was also reflected in the community. This will be outlined in the next section of this analysis.

6.4.3 Limited-service provision.

It was evident from carer data that the isolation experienced in the community impacted on their wellbeing, and the wellbeing of the person living with dementia, particularly in relation to the detrimental impact of lockdown upon cognitive ability. This decline in wellbeing was linked to the absence of service availability and uncertainty around what would be available both immediately, and in the long-term following the discharge. This uncertainty impacted upon decision making during the discharge process because what would be available to carers and people living with dementia, long or short term, was unclear. This made deciding key elements of the discharge plan difficult for carers and professionals, as both care package provision and day centre availability was steeped in ambiguity.

> *Consultant: So, I think that's you know. Obviously, people do clinically deteriorate as well, so that's an uncertainty. But the biggest uncertainty I have at the moment, and the biggest I think frustration in my practice I have at the moment is the availability of community care and that has hugely, hugely deteriorated since COVID.*

Uncertainties around employment caused by the pandemic, contributed to difficult discharge decision making. Carers were uncertain regarding the long-term availability of mechanisms such as furlough. In response to this, professionals tried to counteract the limited-service provision in the community by further signposting, and offering more informational support before the person living with dementia left the hospital setting. Sometimes this was delivered over the telephone to the carer. Another issue for professionals and carers included the uncertainty surrounding funding for discharge, with changing goal posts around funding availability causing ongoing problems.

> *Social Worker 01: Well, it's, it's just, just been extended, because we did think it was only gonna be till 31st of March, so again, we had this scramble to do, to move the reviews and get everybody out of that funding by the 31st of March. And then we're told actually, it's going to be extended, but only for hospital discharge now and not for hospital avoidances.*

Carers and professionals were united in their view that limited community services had led to significant deterioration in people living with dementia, with a corresponding impact on their wellbeing. The lack of respite and services available to carers to pursue relaxation and hobbies during lockdown also caused significant deterioration in carer mental health. The data from both professional participants and carers demonstrated that the ongoing uncertainty around community provision and support, lockdowns and isolation, impacted on the ability of carers and people living with dementia to maintain a sense of hope and plan effectively for the hospital discharge.

> *Specialist dementia nurse 2: And even things like the day centre shutting, those are things that kept people well. Churches shutting, the anxiety around, going to regular services, those things that could have made a mark in your week...... So, then people came in more confused.*

This section has demonstrated the importance of the maintenance of hope in ensuring the wellbeing of people living with dementia and their carer during the hospital discharge process. These findings develop the content of the concept of hope and its value to wellbeing, as outlined by Kitwood (1997), within the confines of the discharge process. During the discharge process, it was identified that considerations beyond just physical requirements were essential for the maintenance of hope for people living with dementia and their carers. The impact of stress on the ability to maintain hope, and the value of health and social care professionals who support the movement towards self-actualisation, were evident within the analysis.

The Appreciative Inquiry method highlighted carer insights into how to maintain hope during the discharge process. Carers identified the value of holistic care and adequate respite availability through their narratives. Further developing this, the importance of a supportive environment financially, and adequate service accessibility, was revealed through the analysis of carer data. One of the strengths of the Appreciative Inquiry method is its ability to focus on context specific strengths and weaknesses (Reed, 2007). I identified the way fear, isolation in the hospital context and limited-service provision, caused uncertainty during the pandemic and undermined the ability of people living with dementia and their carers to maintain hope during this period. This demonstrates the value of the Appreciative Inquiry method for identifying areas that require development within a process and what might be useful to Dream about further.

In the next section, I will move on to elaborate on the second theme identified within the analysis: the importance of ensuring the personal worth of people living with dementia and their carers. Ensuring the personal worth of the person living with dementia and their carer is central to ensuring their wellbeing during the discharge process. This theme reflects the value of person-centred care, communication, safeguarding and the importance of being treated as a true care partner, throughout the discharge process for supporting wellbeing.

Chapter 7. Personal Worth

7.1 Personal Worth

It was evident that ensuring the personal worth of the person living with dementia and their carers was vital to ensuring their wellbeing during the discharge process. The analysis yielded two main themes in relation to personal worth: ensuring person centred care; and that carers and people living with dementia are treated as care partners during the discharge process. The influence of the Appreciative Inquiry approach on the analysis process can be identified in the focus on how to ensure holistic, person-centred care. Table 15 outlines the themes and subthemes of personal worth.

Table 15. Personal Worth. Themes and subthemes.

Table 15
Theme 1 Ensuring person- centred care to support personal worth
Subtheme 1.1 Understandings of person- centred care
Subtheme 1.2 Communication
Subtheme 1.3 Safeguarding as a pillar of holistic care
Subtheme 1.4 Discrimination
Theme 2 Being treated as a care partner

7.2 Ensuring person centred care to support personal worth

This section explores how the analysis revealed that ensuring holistic and person-centred care supported the personal worth of both carers and people living with dementia during the hospital discharge. Person centred care was identified by carers and professionals as including **understandings of person-centred care; positive and adequate communication; adequate safeguarding; and an environment free from discrimination.** I will first discuss the nature of person-centred care as defined and understood by health and social care professionals and carers. As in previous chapters, the analysis of health and social care professional and carer data is presented side by side to highlight where perspectives align or differ.

7.2.1 Understandings of person- centred care

The analysis identified that both professionals and carers felt that person centred care was integral to ensuring the personal worth of both the carer, and the person living with dementia, during the entirety of the hospital discharge process. However, the understood definitions of person-centred care were not identical for these two participant groups. For professionals, person centred care primarily reflected objective concerns, such as centring the person living with dementia through practical actions and decision making, while validating their wishes in conjunction with the needs of the carer.

> *Occupational Therapist: Okay, and what it's very much the client being at the at the epicentre of all discussions and including them as much as possible so that they actually feel that they've got that element of control and that they're still important so, centralizing all discussions.*

From the perspective of carers, person centred care involved feeling emotionally supported with consideration being shown to the individual requirements of the person living with dementia. Kindness, compassion, and taking the time to support both the carer, and the person with dementia was valued. Carers highlighted small, caring actions as epitomising person- centred care. These opposing perspectives demonstrate the differing approaches to this aspect of wellbeing and reveal how the concept of personal worth and person-centred care, is a dynamic entity with multiple meanings. In alignment with the Appreciative Inquiry method, carers were able to identify and narrate specific instances when they felt that they experienced person centred care. This is demonstrated by the extract from Harriet's transcript.

> *Harriet: And it was, you know, they did have the clinical aspect covered. But they also had this very nice kindness and compassion, you know that to me, I don't often meet in the hospital scenario. Because it is more clinical. So, it was the emotional support for me, the emotional support for him, and you know it was all very, very good, excellent.*

Taking time to support carers was identified as beneficial by different health and social care professionals. Professionals were cognisant of the need for carers to receive and understand how to access appropriate support. However, professional concepts of support leaned towards assistance around the processes and conditions of care, rather than the carer focus on emotional support. Professionals identified support as aligning with informational and practical assistance, particularly in relation to understanding dementia as a medical condition and its prognosis. While this is an integral part of the support required by carers, it diverged from the carer focus on intangible, emotional support. Carers identified that true person-centred care moved towards a holistic view of the patient, and a careful consideration of the impact of their dementia diagnosis on their requirements during the discharge process.

> *Specialist dementia nurse 3: Things do change, that we've got access to the support services, so that they're not feeling overwhelmed by kind of the change in care need, or the change in this support that they are having to provide from the care point of view. And can access that help or support.*

> *Katie: The proactive bit is missing.*
>
> *All of these places, and it just makes you worry, to what extent wellbeing is taken into consideration, especially with people with Alzheimer's or dementia. It seems to be that bit just doesn't exist, whereas, that is actually part of the whole thing, as well.*

It was evident from the analysis that the carer definition of person-centred care was vital to ensuring the personal worth of people living with dementia and their carers. Conversely, an absence of person- centred care was experienced by carers as a discharge lacking in basic humanity, with a corresponding detrimental impact on personal worth. Losing valued personal items or having personal items treated with a lack of care was interpreted as a reflection of the worth assigned to the person living with dementia and their carer. Professionals and carers agreed that ensuring person-centred care fundamentally relied on positive and inclusive communication between professionals, carers and the person living with dementia. Carers argued that particularly poor communication resulted in a discharge process that lacked humanity and could be very upsetting to carers with a low tolerance for brisk and functional communication.

> *Jane: I recognize that they're probably stressed and so are maybe not wording things in certain ways that are supportive or that they're not giving, maybe, accidentally not giving, us the opportunity to input into something. Because you know, because they've just not got time and, you know, being bounced around different people at social services, I get it, that it's probably an artifact of a stretched service, but it's still. I felt as if the humanity aspect of it was kind of removed a bit too much, you know, ...*
>
> *I just think that that, like I said, that like, there was just no humanity in it or very little humanity in it.*

The importance of adequate communication in ensuring person centred care shall be considered more explicitly in the next section.

7.2.2 Communication

Communication was often characterised by health and social care professionals as a one-way communication of information, from the health and social care team to the carer and patient. Although this was often framed as a discussion, language choices by professional participants revealed that the professional was viewed as the active communicator within the relationship, and the carer or patient as the passive partner. Discharge targets and goals were largely dictated by the professional member of the communication relationship. Further to this, professionals did not provide clarity in their responses regarding what could be considered 'good communication,' instead leaving the parameters of what constituted positive communication undeveloped.

> *Consultant: So, often on my ward rounds I would say to my patients and their relatives, ok so, like, these are the goals that you need to meet before going home. So, sometimes it's medical stuff, so say, you know, for somebody who is perfectly well and is mobilizing around the ward but is on oxygen, I'll say: 24 hours after you come off your oxygen, you can go home.*
>
> *And, so, the patients know what the goals are, they are trying to meet and what things they need to tick before they can come home. And the carers know that as well.*

Positive communication that enabled person-centred care was highly welcomed by carers. The Appreciative Inquiry process allowed the analysis to identify, through carer narratives, the value of strong person-centred communication and recognise the requirement to build on this aspect of person-centred care. At times, this involved being the recipient of information, but it also involved being listened to, and professionals actively seeking out information from carers and people living with dementia. Nurses were more often identified as communicating in a person- centred way that ensured wellbeing and leading to carers having a positive outlook on the discharge process. Carers had a detailed insight into the ways in which poor communication could prevent person-centred care and undermine the personal worth of both the carer and the person living with dementia. Carers reported that being the recipient of poor communication was endemic within the hospital discharge process, and that this had a significant impact on their ability to prepare for the needs of the person living with dementia on leaving the hospital. Not being informed of changes in the patient's condition, or alterations required to the home to support the discharge, left carers struggling to manage the discharge process.

> *Katie: And the one thing, I think, actually, there was only one time that I felt so reassured, on, on one phone call from one nurse who actually, I think she rang me and just said, I'm looking after your dad and, I just want to get a bit of an insight into how he is with his dementia, and the penny dropped.*
>
> *Somebody has the nounce to ask what kind of things he likes, what is he like and that? Like what upsets him? What's he good at?*
>
> *Jack: It all boils down to a lack of communication or poor-quality communication, that would certainly help, and I would have liked to have had more information up front about what my wife's ongoing needs would be. It came as a bit of a shock to me because, as I say, prior to my wife going into hospital, you know she would go to the toilet.*
>
> *Interviewer: And did anybody have a conversation with you about that or offer you any support when she was coming home?*
>
> *Jack: No. No, no, no, if they could have helped to prepare me and said look, you know, your wife has become incontinent, or her condition has changed.*

Several carers referred to feeling 'out of the loop' and felt that they did not have the relevant information needed to support the person they cared for. This led to complicated and distressing scenarios that could have been avoided through better information sharing. Carers felt that health and social care professionals were not forthcoming with pertinent information, and this led to carers feeling that they did not have a comprehensive overview of the discharge process or plan. Carers even felt that they were treated as an inconvenience at times. Being the recipient of poor communication could lead to long term financial difficulties resulting from the discharge, or immediate problems in relation to medication. Professionals did not discuss the impact of poor communication on the carer or person living with dementia.

> *Carol: People, people aren't always told that it's available. There are grants from the council that will help you modify certain bathrooms into wet rooms and, you know, have handlebars put in. It's all there but it has to be told, about because there's a lot of people out there that's struggling.*

Carers described demanding and even dangerous scenarios resulting from the lack of communication during the day of discharge. Sometimes there were legal ramifications, for example, deprivation of liberty orders being approved without relatives with power of attorney being informed, and only discovering this information at the completion of the discharge process through a third party. Experiences such as these, led to significant anger and emotional distress, undermining any experience of person-centred care.

> *Jane: She says, I bet you didn't know that the hospital, I bet you didn't know that the hospital put a dols on him?*
>
> *A deprivation of liberty order. I said 'no, I bloody didn't', and I, you know. And I said, 'well, we're lasting power of attorney over him'. So never mind. The final word as a family member like, and it's not like I would have opposed it. Of course, I wouldn't have, but it's like, well, you've got to involve the family.*

These dangerous scenarios reveal the absence of safeguarding, at times, for people living with dementia and their carers. I shall discuss this finding further in the next section.

7.2.3 Safeguarding as a pillar of person-centred care

It was apparent from the analysis that safeguarding the person living with dementia and their carer is a pillar of person-centred care, which indicates an integral regard for wellbeing. Health and social care professionals also stated that adequate safeguarding was a key stone in ensuring the wellbeing of people living with dementia and their carers. NHS England (2022b) defines safeguarding as 'protecting a citizen's health, wellbeing, and human rights', and it is this definition that I will employ in this section of the analysis.

Some professionals believed that they safeguarded carers by asking questions about their ability to care. However, carers identified multiple occasions where safeguarding did not occur during the discharge process. Carers were distressed and angry at the absence of safeguarding both for the person living with dementia, and themselves, and at the lack of consideration for both. Sometimes safeguarding was apparent, as in the example given by Elizabeth, who was asked when would be appropriate for her relative to be discharged, and who experienced a delay in discharge over a weekend to safeguard both herself and the person she cared for. This was appreciated as a sign of valuing carer and patient's personal worth. This instance is highlighted, in accordance with the Appreciative Inquiry method, as it details how safeguarding can be built upon with the discharge process.

> *Jack: At about three o'clock in the afternoon on Monday I had a ring on the doorbell. And then I went to the door, and lo and behold, there's my wife in a wheelchair with two transport drivers. And they knocked on the door and said, this is *** we've brought her home. And I was quite angry, because I mean, obviously, I was pleased, she was home. I asked them why I wasn't alerted to the fact that she was coming home, and the usual thing was, we had nothing to do with it, we're just following instructions.*
>
> *But what annoyed me was, I could have been out of the house. And, you hear some horror stories about people being left on the doorstep and things.*
>
> *Amy: Afterwards, a concern was the fact that they released an elderly 95-year-old lady with a broken hip and Alzheimer's, into the care of one individual. And that individual they made no, I mean, I've got arthritic knees, which makes things difficult and I'm having to go up and down the stairs, uhm like a jack in the box and*

> *umm but one person, and what if I had a heart [condition], I mean they didn't' ask me?!*

Related to an absence of safeguarding, health and social care professionals also described experiences of discrimination. These experiences shall be discussed in the next section of this chapter.

7.2.4 Discrimination

Some professionals identified that discrimination within the health and social care team could create a barrier to ensuring person centred care, and to maintaining the personal worth of people living with dementia during the discharge process. This discrimination was also felt within carer data, with some carers believing that health and social care staff perceived patients with dementia as 'extra work' (Shelly). Some carers identified that prejudiced beliefs about being unable to live independently in the community, led to care home discharges. This discrimination was viewed as devaluing both the personal worth of the person with dementia and the opinion of the carer. However, discrimination was not discussed by the majority of carers who attributed poor experiences of person- centred care to the hospital system or to a stretched service.

> *Specialist Dementia Nurse 3: Not all of the teams, but you do find sometimes that, the patient you know they might be 95, and been living really well at home. But there is still that stigma attached, if someone's had a hospital admission and how are they coping, or do they need 24-hour care?*
>
> *I think sometimes there's still that kind of quick, quick rushing and looking for 24-hour care placements. Rather than looking at how really restrictive it might be. So not always, especially when people have got a dementia diagnosis, there is still that stigma there.*

> *Shelly: They just weren't helpful. They just weren't helpful with her, I always feel like, is this ever going to change? Because people don't really tolerate dementia. And I'm being honest. I think its, forward staff, and this is wrong, but I think they, they see patients with dementia as 'extra work' compared to other patients, which is wrong. They actually said my mom was a wanderer, which she wasn't. And that really riled us. It's people's perception of what dementia is about.*

In this section, the Appreciative Inquiry approach enabled the identification that person centred care is vital to ensuring the personal worth of the person living with dementia and their carer, during the hospital discharge process. Person centred practices, involving positive communication, were identified as vital to ensuring the personal worth of carers and people living with dementia. These strengths must be built upon in accordance with the Appreciative Inquiry method. Further focus on ensuring adequate safeguarding, and the removal of discrimination was identified as important for supporting the wellbeing of the carer, and person living with dementia. In the next section, the importance of being treated as a care partner will be outlined.

7.3 Treated as care partners

Carers valued themselves, and the person living with dementia, being treated as joint care partners, and identified receiving such regard as crucial to their own wellbeing, and the wellbeing of their relative living with dementia. Being equitably consulted by professionals in relation to key decisions was a significant aspect of this. Consideration of the needs of the individual with dementia and their carer, was vital to feeling regarded as a care partner and this respect could help engender positive feelings of wellbeing. In accordance with the tenets of Appreciative Inquiry, this experience of being treated as a care partner can be identified as a potential strength of the process. The actions of individual professionals were identified as crucial in ensuing equality within the care partnership.

> *Elizabeth: One of the most well, I think one of the most exemplary things was when my husband was ready, medically fit for discharge. This was the Friday before the bank holiday, and the consultant on this ward just said to me, you know you can go home whenever you're ready. If you want to go home. As soon as, you think you've got the care package re- started. It's just one of the most trusting things, I think it really resonated with me.*

Conversely, not being treated as a care partner could have a detrimental impact on wellbeing. An unequal power dynamic resulting in carers feeling bullied within decision making or being dictated to during the discharge process was highly detrimental.

Carers also discussed their sense of being marginalised when challenging professional decision making, and the emotional impact of this.

> *James: I think the worst point for me, there, was being told that if you don't go along with what we want to do, which was take her to a care home. I said, I've got power of attorney, I'll just take her home and look after her, I've been looking after. They said, we will take you to court and overturn the power of attorney. This is the hospital!*
>
> *Jack: It was almost like, it's a fait accompli, by the way, she's coming out, you know. Bits of information was given to me, but I didn't feel I had much of a choice of what's going to happen. And what probably upset me to some extent was, I'd fought to try to get her out of hospital for so long. When I was kind of getting brushed off, you know. It's not, not happening,* ***we're making the decisions.***

It was evident from the analysis that professionals had a clear perception of the value of carers and people living with dementia as care partners. Professionals also identified that maintaining trust was significant in treating carers and people living with dementia as care partners. Working together towards shared goals was a key component of working in a care partnership for professionals. Ensuring decision making was shared between professionals and carers and people living with dementia in an equal tripartite formation, was identified as important within the partnership. The Appreciative Inquiry method enabled the identification of the value of working in partnership with carers and people living with dementia.

> *Consultant 01: She was discharged home from another trust. And then her son brought her to our trust because he lost all faith in the other trust. And it was things like, there wasn't a recognition that this lady was continent before she came in, and she came out of hospital, doubly incontinent, and the continence issue was never explained to the son. And actually, we've managed to get her continent of urine not bowel management, so it's, it's having that really good prior information. Um, to, assess what your goals are and what you're working towards.*

However, professionals acknowledged that there were times when carers and people living with dementia were not treated as care partners. There was an acknowledgement that choice was often not available within decision making, and that carers and people living with dementia are often overruled by professionals within the medical hierarchy. Financial constraints were also pinpointed as undermining the care partnership. The lack of choice cited by professionals reveals the absence of agency. This will be explored further in the next chapter of the findings, where the importance and facets of the third theme will be explored.

> *Nurse 01: We've referred to social workers to kind of, they're important for all, that she's said twice a day, or less.* ***But we've kind of taken that out with her hands now*** *and kind of said, I think three to four times is probably what you'll need.*

The value of ensuring the personal worth of the person living with dementia and their carer through an emphasis on person centred care, communication, adequate safeguarding and vigilance against discrimination, has been demonstrated as vital to ensuring wellbeing during the discharge process, within this section. The approach of the Appreciative Inquiry method has enabled the identification of these potential areas of strength within carer and professional narratives. The importance of being treated as a true care partner during the hospital discharge process has also been determined. Acting as a true care partner involves ensuring that agency is protected for both the person living with dementia and their carer. The facets of maintaining agency during the discharge process, shall be explored in the next chapter of the findings.

Chapter 8. Agency

In this section of the findings, I will discuss the importance of carers and people living with dementia maintaining agency during the hospital discharge process, and the ways in which the process can be empowering or disempowering. Four key subthemes were identified within the analysis; supportive professionals and interprofessional working enabling empowerment; empowering processes; contexts that enable equality and risk taking, and COVID 19 and the prevention of agency. Once again, within this section of the analysis the Appreciative Inquiry approach of identifying and building upon apparent strengths was utilised. It was evident that health and social care professionals believe that proactive individuals, across professions and the hospital community divide, were central to ensuring the agency and the wellbeing of carers and people living with dementia. The weaker aspects of the process are also detailed as it is important to acknowledge and learn from these also (Havens, Wood and Leeman, 2006). As in previous chapters, carer and professional perspectives are presented simultaneously to enable comparison. Table 16 outlines the agency themes and subthemes.

Table 16. Agency. Themes and subthemes.

Table 16
Theme 1 Supportive health and social care professionals enabling empowerment
Theme 2 Empowering processes
Subtheme 2.1 Disempowering nature of bureaucracy
Subtheme 2.2 Medication as a potentially disempowering factor in the discharge process
Subtheme 2.3 The empowering or disempowering process of planning the discharge process
Subtheme 2.4 The day of discharge and its potential to undermine the person living with dementia and their carer
Theme 3 Contexts that enable equality and risk taking
Theme 4 COVID 19 and the prevention of agency

8.1 Supportive professionals enabling empowerment

The benefit of strong, positive relationships and communication, between different health and social care professionals was evident from the analysis. Excellent teamwork between different specialist professionals was identified as crucial to ensuring solid discharge planning that ensured the wellbeing and agency of people living with dementia and their carers. It was identified as essential that specialist dementia teams are involved in the planning of the discharge process. Moreover, the role of the nurse as the central organiser in the discharge process was discussed, alongside the benefit of experienced professionals, and the input of the wider working team. Proactive professionals focused on planning the discharge process thoroughly were identified as important during the organizational process. These identified strengths were apparent throughout the Appreciative Inquiry influenced analysis process. The complexity of the organisational process was evident, alongside the need for enhanced skills and organisational ability from the discharging nurse. The data extract below reveals the attention to detail required by the discharging nurse to ensure that the discharge is organised efficiently.

> *Specialist Dementia Nurse 5: Our role is as a dementia care specialist team. So, part of that would be supporting the clinical teams in enabling them to, I suppose, look at that, the kind of correct, more support is in place at discharge, to see is the aim is for the person to go home or return back to their, the residence where they were admitted from.*

Carers had an awareness of the importance of interprofessional working, particularly between the acute and community settings. Elizabeth experienced fast and effective interprofessional communication, between the community and hospital sector, that ensured an efficient and positive discharge experience, and this was identified as a significant strength. By contrast, Jane felt that there was limited effective interprofessional working between the hospital and community. Carers focused on occasions where supportive professionals enabled them to care for their own and their relatives' wellbeing, and on occasions where professionals did not enable this.

Compassion was singled out as an important quality during the discharge.

> *Elizabeth: The consultant saw me in the corridor at 12 o'clock one day, when I got home from visiting that evening, I got a telephone message saying, 'I'm going to speak to the GP', because apparently the hospital at home team had to be referred to by the GP because that's another process. So, I got home in the evening, there was a message on my answering machine from the GP saying, 'I got an email from the consultant, could you make an appointment?' The GP is only around the corner, I popped into the GP'S at 8am the next morning to say the GP wants to have a word with me. The receptionist scheduled an appointment for later that morning. So, within 24 hours. I went back to visit my husband and the GP had spoken to the consultant again and within 24 hours, the consultant, the GP and me and the home care team plan had all been put into place.*
>
> *Interviewer: That's brilliant*
>
> *Elizabeth: So, my husband could come home that evening.*

> *Jane: But like I said, I just got the impression it was red tape and it was the hospital saying he can be discharged from today or whenever, you know, imminently. I got the impression that there was no opening of channels of communication or what's the word? Negotiation about, well, can you keep him a bit longer? Or you know, this is this situation. It was just. You know it was there, there wasn't, there was no interprofessional communication.*
>
> *Interviewer: And they're not communicating with one another at all?*
>
> *Jane: Or with me. Yeah, so there you go.*

Poor interpersonal relationships, or inconsistency with professionals, was characterised as problematic and detrimental to the agency of the carer. Engaging with a multitude of different social workers or district nurses was frustrating for both Katie and Carol, who both felt they could not build any relationships and were left repeating themselves to different professionals.

> *Katie: And that was extremely frustrating because I had to repeat over and over and over again, to a different person every day, what was going on, what help was needed in fact.*

Carers discussed how the actions of professionals could leave them feeling undermined. Katie felt that social workers listened to her father, who lacked capacity, and other care professionals, rather than herself, which was frustrating as she believed she was best placed to know her father’s needs and wishes. Carers specifically mentioned poor interpersonal skills, in relation to working and communicating with people living with dementia, as particularly detrimental to wellbeing when the person was being discharged home. Jack felt that carers with poor communication skills could act inappropriately, and potentially neglectfully, to his wife during personal care sessions.

> *Katie: the social worker had to go inside the care home and have a meeting with the care home manager to corroborate with what dad had just said and she was in there for quite a while. She came out, back to the car park and she said, well, I've had a long conversation with the care home manager, and she believes that your needs are being met fully here and she has concerns that you wouldn't settle in the new care home. Me dad actually had the best line going and he said, ‘well, I'm a big boy now and I think I know where I’d be better’.*

While Health and Social Care Professionals were able to act in empowering ways, processes were identified as having the ability to promote or prevent agency for the carer and person living with dementia, and this shall be further discussed in the next section.

8.2 Empowering processes

It was found that the processes of discharge could be empowering or disempowering, and crucially, that they can safeguard or harm the wellbeing of people living with dementia and their carers. The subthemes identified included: the disempowering nature of bureaucracy; medication as a potentially disempowering factor in the discharge process; the empowering or disempowering process of planning the discharge process and the day of discharge, and its potential to undermine or support the person living with dementia and their carer. In accordance with the Appreciative Inquiry method, this section identified both the strengths and weaknesses of the hospital discharge process. Table 17 details the empowering processes subthemes

Table 17. Empowering processes subthemes.

Table 17
1 Disempowering nature of bureaucracy
2 Medication as a potentially disempowering factor in the discharge process
3 The empowering or disempowering process of planning the discharge process
4 The day of discharge and its potential to undermine the person living with dementia and their carer

Professionals had detailed insight into the processes that could support the agency and wellbeing of people living with dementia and their carers. Professional insight into the discharge process was often more nuanced and detailed, regarding the mechanisms of the process itself, than the insight of carers. Professionals identified that explicitly transparent processes, involving the multidisciplinary team and with the involvement of a discharge co-ordinator, alongside formal meetings involving carers, and the dementia specialist team are crucial to ensuring an empowering discharge process. These strengths of the process were evident using the Appreciative Inquiry method. Equally, professionals were critical of overly bureaucratic systems which could disempower both the individual living with dementia and their carer. The analysis of the data from professionals revealed that the discharge process itself was often taking precedence over the individual living with dementia and their carer. This can be identified as a weakness of the process (Reed, 2007). This section shall firstly consider the impact of bureaucracy on the ability of the person living with dementia, and their carer, to exercise agency.

8.2.1 The disempowering nature of bureaucracy within the discharge process

The cumbersome bureaucracy of the discharge process was singled out by both carers and professionals, as causing significant disempowerment for both the person living with dementia and their carer. High levels of bureaucracy led to difficulties for professionals within their own practice, which impacted on their ability to facilitate the agency of people living with dementia and their carers. Bureaucracy relating to communication between different local authorities and around different systems within certain services, was mentioned and understood as ‘red tape’ (Jane) which could be difficult for carers to navigate. Understanding the bureaucratic barriers themselves and learning how the system worked, was identified as time consuming and undermining the ability to organise an efficient discharge.

> *Elizabeth: So, he had to, my husband, had to change his GP from one borough to another just so that the district nurse could come in.*
>
> *But it's sort of things like that. You know, it takes a while to even understand what the issue is before you find out what the way round it is.*

Bureaucratic rules were a significant hurdle to ensuring a smooth discharge process. Rules regarding which services could communicate with each other were highlighted as a particular barrier to ensuring appropriate referrals, and adequate communication. The overt bureaucracy embedded within financial decision making was particularly disempowering, with the process for applying for finance arduous and often futile. Overly long, complex documentation relating to financial assessments was criticised as making the process opaque and taxing to understand.

> *Specialist dementia nurse 4: Well, so, because the discharge processes is managed by the hospital, social workers they can't refer to a day centre. So, then, we would have to do a referral to the community social workers to ask them for a day centre.*
>
> *Jack: So, they sent three files. I don't know if you have seen these documents. But one separate document, I think, is 45 pages long. And the explanation documents are another 20 odd pages, and I had no option but to print them out. They’re too long, I can’t read them on a screen.*

Alongside overly long and difficult documentation was the complexity linked to understanding medication schedules.

8.2.2 Medication as a potentially disempowering factor in the discharge process

The analysis showed that obtaining the correct medication was a challenging aspect of the discharge process. Receiving medication with little explanation and last minute, was heavily criticised by carers, and identified as causing significant complications at the point of discharge. Medication changes which were not explained to carers were identifiable frequently within the data. Some carers were astounded that people living with dementia could be discharged without prescribed pain medication, and with no explanation of the medications provided. Others described inappropriate medication in relation to continence being prescribed resulting in problems which later had to be addressed post discharge. Professionals acknowledged some of the problems related to medication distribution and how last-minute changes by medical staff could lead to confusion and delays. However, there was limited discussion of the medication distribution process from professionals, in comparison to carer narratives, suggesting a limited awareness of the negative impact on carers and people living dementia amongst health and social care professionals. Negative experiences were not universal, and the empowering nature of medication processes that considered the needs of the carer, and the person living with dementia, were evident in some carer narratives where integration between the community pharmacy and hospital pharmacy was praised. This was identified as a particular strength of the process.

> *Harriet: we had the discharge note with the medication and we had what was already in his medication draw in his dresser. And we were trying to reconcile them both. And at first, they couldn't help us but we kind of said look, this is a Friday afternoon, he's got to be sorted out for the weekend medications and they agreed to get somebody to ring me. Obviously, that took time, so you know we were sat, still sat on the floor, surrounded by the medication and some of the meds I was familiar with, like the diabetes medication but the heart failure medication I hadn't a clue. Giving somebody a huge bag of medication without any instruction is just not on.*

> *Interviewer: Did you have any kinds of issues with the medications, were the medications always quite well explained?*

> *Elizabeth: The medications were always very well explained, my husband was put on to insulin at one point and the district nurses and the hospital taught me how to do that, so I did that. the hospital pharmacists were very good at explaining the medication changes to me before discharge.*

Whether the medication was explained to carers adequately was related to wider issues concerning the strength of the discharge planning. This shall be considered further in the next section.

8.2.3 The empowering or disempowering process of planning the discharge process

The planning process of the discharge was heavily criticised by both carers and professionals, and the analysis of the data showed that the planning aspect of the discharge was central to delivering an empowering, or disempowering experience, for carers and people living with dementia. The discharge planning process was described as long and protracted for people living with dementia, involving significant assessment and paperwork. Utilising the Appreciative Inquiry approach and the need to Dream (Carter *et al*, 2007), professional participants identified that the discharge process could be better organised, with professionals themselves having a clearer understanding of each other's role and a more transparent timeline.

> *Specialist dementia nurse 3: For patients who are going into a completely new care setting, that's when things become protracted, so going to a new residential care home or intermediate care bed can all be quite a long process.*
>
> *Specialist dementia nurse 3: Yes, so lots of care facilities will ask for completed behaviour charts, completed nutrition charts and then we'll do the assessment forms. They have to be agreed by the hospital and shared with the family and agreed by the family, to make sure that we've identified everyone's care needs appropriately, then they have to go to a panel. They have to be agreed at panel around funding. And people who are self- funded there's more financial assessments to be done, and then we have to find availability in a home that somebody would choose to go to.*

It was identified in the analysis that professionals had a good insight into what enabled a 'good', functional discharge process that worked well. Operating the Appreciative Inquiry approach, Professionals identified the strengths of the process to include discharge meetings involving the carer, person living with dementia and multidisciplinary team, involvement of the specialist dementia team in the discharge planning process, planning from the beginning of the admission, and a designated discharge co-ordinator, with a single point of contact. Shared ward rounds and supportive technology were also particularly praised. The involvement of the specialist dementia team was characterised as enabling advocacy for the person living with dementia, and the identification and referral to services and support structures that could enable wellbeing in the community post- discharge. The role of the discharge co-ordinator in the process was particularly valued by professionals and identified as a strength of the process where available.

> *Specialist dementia nurse 3: And we've got a designated discharge coordinator for each ward. And they only do a rotation every three months. So, they get to know the patients as well as we do. They join the ward round every day. We have a ward round Monday to Friday. So, in that ward round, they can give the discharge update so everybody knows, and we've got quite a good patient information board that we can update as new information comes in, the OT can confirm delivery of equipment with the discharge coordinator, but also, you've got that one person who knows all of that information.*

Setting discharge goals with the involvement of carers, the person living with dementia, and the multi-disciplinary team were characterised as being very important. Working together to ensure a holistic portrait of the person living with dementia was considered vital to an empowering discharge process.

> *Specialist dementia nurse 1: It's really important to involve everybody. So, what we try and do it, so we have a weekly MDT on each of our wards, where we have therapists, the medical team, the nursing team, and the specialist. So, we have a really 'holistic view of the patient' and then normally either my job or the discharge team's job is to ring the carer to find out how they're managing, how they're coping. And how they see things in the future, because actually there's no point in that, in somebody up for discharge home, if the carer really can't cope with them coming home so. Yeah, and **you have to have a decision between all of you.***

The analysis showed that professionals characterised meetings as central to ensuring an empowering discharge process. Contrastingly, carers characterised meetings as having the potential to be profoundly disempowering. Many carers had never attended a discharge meeting or been offered the opportunity to attend one. Conversely, carers who had attended a well-planned, MDT discharge meeting had a fulfilling and empowering experience, which they believed had ensured a successful discharge. However, other carers detailed how they were undermined in the discharge meetings and felt that the professional staff, and discharge system, was actively working against them during this period of vulnerability. This reveals that strengths can be experienced as weaknesses for others, in correspondence with the social constructionist and Appreciative Inquiry approach. Therefore, it is important to seek multiple perspectives to give a fuller picture of a process.

> *Interviewer: So, there was a big discharge meeting and what kind of happened there?*
>
> *Elizabeth: It was, the consultant convened it and it was a big inter-professional meeting and there was a physio and an OT, the consultant, and the ward sister. And somebody else and myself, and another relative and I say, that was my husband was significantly more diminished than he had been on admission and the consultant, an experienced geriatrician, was unsure that we would be able to manage at home, thought we should perhaps be looking at a nursing home. But he said he was prepared to let us try managing at home on the understanding that if he wasn't confident that we would be able to manage and I think if we'd had different calibre local authority carers, we might not have managed, you know. .....*
>
> *Interviewer: It sounds like you had some good support and the discharge planning meeting, did you feel like it was kind of a two-way conversation as well, where you could kind….*
>
> *Elizabeth: Oh yes. It was an experienced consultant who took on the views of the rest of the team. We also had a social worker there who I think was a good old-fashioned social worker who knew her stuff even, even, you know, coming home to start with, it, it. It was only after then when I realized, I compared my experience with the experience other people with having. I think it was, it was the initial discharge planning meeting. It was well planned [the discharge] and also, I think what was available to us, it was like a one stop shop.*

> *James: And I was invited in, during visiting time in the afternoon, but in the morning and there were 8 people sitting in the patient visitors room and they were all to see me and 8 people felt that it was necessary to have 8 different experts in a room with me representing my mom, just to get it across to me that you're not bringing your mom home, she is going in a care home.*
>
> *Prior to the NHS job, I worked 16 years in legal aid. It's called inequality of arms. it's someone who can afford the best barrister against you acting in person.*
>
> *Luckily, I've had some experiences of dealing with this kind of situation before, but I thought afterwards in a quiet moment, I thought, how, if this is how they go on, how should that make other people feel, you know, I'm trying to cope with the fact that my mom's not coming home.*

In contrast to professionals, carers felt that there was little planning ahead of the discharge, particularly in relation to the date of the discharge. Some carers were sceptical that there was any detailed planning occurring even where there was a legal obligation, and others felt that if planning was taking place, it was taking place too late. If there was discharge planning occurring, some carers argued that it did not involve them.

> *Jane: And it's, you know, we hear about discharge planning, we hear about, you know all the kind of guidance about that and it's like, well, nobody planned his discharge from what I can see, and actually, you know, if even if somebody planned it, they didn't involve the multidisciplinary team that included social services in that if you see what I means, and they didn't bloody involve us.*
>
> *Me, little old me. Uhm, you know who has to live with this afterwards,*
>
> *Interviewer: Yeah, and the funny thing is when I interview professionals and you say, so what do you do to support carers? They say well from day one we involve them in the process. We make sure they're always involved in the process. We talk everything through and then we make decisions together and start planning for them.*
>
> *Jane: Bollocks [laughter].*

However, some carers did feel there was excellent planning occurring that was adequate and considerate of patient and carer needs. Admiral nurses were singled out by multiple carers as central to an empowering experience, although carers felt this might be due to the dedication and personality of the individual nurse. This suggests that good planning can enable an empowering discharge process for both people living with dementia and their carers. This highlight a strength of the process that can be built upon further in accordance with the Appreciative Inquiry method.

> *Michael: Well, you know, without the admiral nurse, to be honest, I wouldn't have, he was advising all the way through, and that was, that was that was great, and he called in once a week to see my parents.*

> *Interviewer: And what did you think was the best part of the discharge process, a part that worked really well?*
>
> *Elizabeth: I think it has to be the initial planning because, that's the comprehensiveness of the initial planning, is what got everything in place.*

The analysis showed that both carers and professionals believed that the planning of the discharge process was driven by finance and pressures around hospital bed availability and clinical staff availability. Professionals discussed their responsibility in relation to the management of public funds and the limited choices available to them during the planning process. There was also significant criticism of the 'gap' that was identified between the hospital context and the community, with carers describing a 'hiatus' (Harriet) of clear responsibility during this period. Carers discussed that not only did they often feel uninvolved in the discharge planning process but that the concerns of the process itself seemed to be dominating the discharge, rather than what they felt was vital to the process themselves.

> *Harriet: So, you know, there was quite a bit of hands-on help for him but you know that there is, I can only describe it as a hiatus that care of the hospital- to care in the community isn't very good.*

> *Amy. And the thing they were obsessing over, when my mother was being released from hospital, I should say being discharged, seemed to be whether she could go upstairs….. I assumed that there would be a point when they would say, she will be released in the next ten days. These are your options. And if the option of a care placement had been raised, I would have gone for it, even though we would have to pay. There was no mention of anything*

> *like that at all. It was more about how high was the bed and how high is her chair when you sit on it?*

Professionals and carers disagreed significantly in relation to the discharge process during the pandemic. Professionals felt that the discharge to assess model introduced during the pandemic was a positive development within the process. However, carers had a contrasting opinion, and felt that the introduction of a discharge ward made communication, and obtaining relevant information, more complex.

> *Specialist dementia nurse 4: Randomly, I think the best features are that we aren't keeping people in hospital to do 1600 tons of paperwork, which then goes to panel and is either passed or not passed, and then it goes to brokerage while people look for a care home. For me it makes sense, they go to a bed to await a placement from the community, which is brilliant and is much, much better.*
>
> *Harriet: The discharge ward didn't know enough, because he hadn't been on there long enough for them to really get to grips with the situation. So, it's this thing of being on a phone and them re directing you back and forth to try and resolve it.*

It was apparent from the data that carers and professionals had conflicting views of the processes underpinning the discharge process. While it was clear that these processes have the potential to be empowering, many of the processes can be enacted in ways that disempower both the person living with dementia and their carer. This reflects the importance of reflecting, within the Appreciative Inquiry process, on the subjectivity of experience and that strengths of a process can also function as weaknesses. The day of discharge itself was highlighted as a potential source of disempowerment, and this shall be explored further in the following section.

8.2.4 The day of discharge and its potential to undermine the person living with dementia and their carer

The analysis revealed that professionals had a detailed insight into the organisation and multitasking required to ensure a smooth process on the day of discharge. However, they were critical of the way the day itself can be dictated by perceived bureaucratic processes, linked to the availability of care packages, service ‘pressures,’ and the added time pressure to complete the discharge. Professionals expressed a sense of frustration with the day of discharge itself and the difficulties of very last-minute organisation processes. Being extremely well organised was cited as crucial to ensuring success on the day of discharge when professional participants were asked to Dream of potential improvements to the discharge process.

> *Interviewer: On the actual day of discharge itself, what do you think are kind of the most important factors to make sure that that goes as smoothly as possible for the patient?*
>
> *Specialist dementia nurse 2: Everyone knows what's going on. So, the problem we have is social services will often only confirm packages of care the day that somebody is leaving. They can't always do that the day before, so, then it's always a bit of a rush to make sure family members know. Make sure heating is on, that somebody has access to a property, all of those things often can't, you know, if somebody's got certain medications, they can't. They can only be made ready on the day somebody goes home.*
>
> *So, for me, I think you know, the things that it would be really nice, if we had an extra 24 hours when we get that call to say everything's ready, just to prepare a patient, make sure they've got, you know, suitable outdoor clothing, making sure that somebody is, if they can meet them at the other end. Whereas however well we've planned somebodies discharge here until we've got that confirmation of the package of care. We can't send somebody home. ….*
>
> *But then because there are pressures, we're not in a position, once we know that, to keep a patient to the next day.*

The process on the day of discharge itself was particularly stressful and opaque for carers. Feeling rushed and disorganised was mentioned as a significant feature of the day. The lack of organisation, and last-minute nature of the process, led to a stressful experience for both carers and people living with dementia.

> *Amy: As I say, it all seemed a bit rushed. I found out around 1pm the day before that my mother was going to be discharged and it wasn’t a question of she’s going to be discharged, you have a choice of this that or the other, it was she’s going to be discharged and that’s it.*
>
> *So, on the day, it felt like people coming and going all the time, delivering things. You could hardly rest between visits. It was*

> *difficult making my mother comfortable because she had come home, and I was sort of dealing with people all the time. I was shocked at how frail she was, and I was shocked that they thought she was fit enough to come home, and to a home that no one had looked at.*

Transport was identified as particularly problematic by both professionals and carers. Professionals cited limited transport options as a source of delayed discharges. Carers found sourcing transport difficult and a source of conflict with hospital staff. The discharge letter was singled out as particularly disempowering by several carers and painted as being responsible for a number of difficulties during the discharge process. The lack of information pertaining to social care issues, or any information outside of the medical status of the patient, was highlighted as particularly disappointing. Another issue was the incorrect identification of the next of kin.

> *Specialist dementia nurse 4: And that we have to allow transport to get somebody out of the hospital in order to be home for the last care visit, or if they're going to a care home they have to be there before a certain time. And if there's a hold up in your transport that will all go totally pear shaped.*

The day of discharge could be a disempowering experience for carers and people living with dementia. Alongside this, concerns about risk could also lead to an absence of agency. This is considered further in the next section, which considers the importance of risk taking during the discharge process for people living with dementia and their carers.

8.3 Contexts that enable equality and risk taking.

Many professionals identified that a key barrier to maintaining agency and wellbeing was the excessive focus on the minimalization of risk within the discharge process. The Appreciative Inquiry method enabled the identification that a context which enabled risk taking, and therefore equality between the wishes of carers, patients, and the concerns of professionals, was vital to ensuring the agency of individuals and maintaining their potential for wellbeing during the discharge process. Professionals identified that this was an issue specifically for people living with dementia and their carers. The analysis showed that professionals often demonstrated a risk averse attitude towards the discharge process for this patient-carer dyad.

The dichotomy between ensuring safety and taking manageable risks, surfaced frequently in professional opinions of decision-making regarding discharge destination. Many professionals appeared to be stuck on the concept of physical safety as the primary concern within the discharge process. The concept of ‘safe’ (Nurse 01) arose multiple times within interview data. The person living with dementia being at risk of a potential fall was a prime concern for professionals, with concepts of safety being given priority above wellbeing and agency during decision making. The safety of carers was also given extensive consideration by professionals. At times, it appeared that coveting complete safety was prioritised above the wishes of people living with dementia and their carers. One nurse referred to safety concerns as a barrier, and it was clear that safety interests were used as justification for decisions made in relation to discharge destination, and the removal of agency for the carer and person living with dementia. Sometimes it was clear that concerns about risk and preserving safety were removing choice in ways that had a significant impact on the person living with dementia, such as taking away the option of using stairs.

> *Nurse 01: So, probably the lady who wants her husband home, while we said* ***it’s not safe*** *like, I don’t know how realistic her image of her husband is now.*

> *Occupational Therapist 1: Yeah, it is, I mean, there are obviously some stages where we have to make some best interest decisions, where the client’s not able to assess the risk accurately for themselves. And may, their wish may be to still use the stairs because they’re convinced, they can use the stairs, but in reality, they’re no longer safe.*

Carers were critical of how decisions were made due to concerns around physical risk dominating wellbeing perspectives. Both professionals and carers recognised that concerns about the risk of falls could lead to decisions being made which supported a care home placement at the point of discharge. Some professionals were very critical of discharge decisions made in relation to the risk of falling that led to care home admission and felt that more risk should be tolerated to enhance the wellbeing of the carer and the person living with dementia. Conversely, some carers did interact with professionals who supported taking risks for the benefit of the carer and person living with dementia. Carers appreciated when there was a tolerance of risk during the discharge process due to the positive impact on the discharge outcome. Carers, such as Elizabeth, felt that tolerance of risk allowed her and her husband the chance to attempt a home discharge which was ultimately successful. This positive story of risk tolerance during the discharge process has been highlighted in accordance with the Appreciative Inquiry method.

> *Elizabeth: At what point the decision is made, what are the criteria for making the decision that somebody should no longer try and be mobile, mobilized and become either chair bound, or bed bound because it has a major impact on quality of life and health and wellbeing, because, you know, it has an impact on your blood pressure and everything. And I can see it from a pure health and safety, risk assessment point of view, health professionals have to make that decision. I didn't see any evidence of that decision being reviewed at any point.*

> *Specialist dementia nurse 3: I think we have a real issue with people not taking risks. Sometimes, I do think, take really big risks, because actually, you know, if that's something that the person, really, really wants but it probably won't work, I think we should still sometimes take that risk, because it's actually, it's really important to that person. And being at home in their own home, even if it was, the risk went to the point where they died, they might still be happier with that decision, than to be removed from their home and going to die in a care home.*

The reluctant attitude to risk taking amongst health and social care professionals was evident in relation to the pandemic. Professionals discussed how the prioritisation of safety within decision making, and the low tolerance of risk, led to decisions that did not prioritise the wellbeing of the person living with dementia, or their carer, or allow for agency. Professionals discussed how people living with dementia were being moved frequently to, 'keep them safe', from the pandemic at great detriment to their wellbeing. The pandemic context led to professionals expressing fears around their ability to adequately safeguard during the discharge process due to limited face to face contact. Professionals stated that they felt there needed to be a balanced approach between the risk of COVID 19 to the patient, and the benefit to their wellbeing of ensuring agency during the discharge process. The impact of COVID 19 on the agency of the person living with dementia, and their carers, will be considered further in the next section.

> *Nurse 01: Because of the pandemic, we can't allow visitors except for exceptional circumstances, whereby somebody is dying. And for patients with dementia, just because they've got dementia, we can't let a relative on the ward, which would be something which would be a comfort. Unfortunately, we are just trying to keep everybody safe.*

8.4 COVID 19 and the prevention of agency

Based on the analysis, it was evident that agency during the pandemic was understood to be significantly curtailed by both professional and carer participants. The continuously changing COVID 19 policy regulations (Department of Health and Social Care, 2020a) limited the degree to which carers, and people living with dementia could assert their independence within the hospital discharge process. The restrictions implemented around visiting were identified by both groups of participants as particularly preventative in relation to the facilitation of the discharge process. The data revealed the dominance of COVID 19 policy (Department of Health and Social Care, 2020a) concerns above the needs of people living with dementia and their carers.

In this section, I will outline how the policies related to the pandemic impacted on the ability of people living with dementia and their carers to exercise agency within the discharge process. This includes how the policy of no visitors in hospital impacted on the ability of professionals to build relationships with families and access important information about patients and carers, the impact of shortages of staff and equipment, the impact of Personal Protective Equipment, the experience of pressure to organise a quick discharge, an absence of community services in the pandemic, and the inability for face-to-face interprofessional working.

> *Specialist dementia nurse 2: Tends that you take much longer to get them back to what you think is a baseline but unless you've got that sort of interaction with carers, you haven't got that and then the support during the discharge process is just not there.*

The difficulties of appropriately organising the discharge process without the ability to consult with a wide pool of relatives and carers face- to- face were apparent. Some professionals discussed how this prevented personal relationships forming between health and social care professionals and carers, and how restrictions prevented a true understanding of the discharge circumstances. Other participants discussed how a dearth of visiting options meant that even autonomy around small aspects of the discharge process, such as clothing choices at discharge, was very limited.

> *Consultant 01: So, I mean it is getting a bit better now, but the visiting restrictions were really, really, hard and it's hard to plan a discharge if you've never met the carer.*
>
> *And I also think that health care, the provision of health care is significantly relationship based and it's really hard to develop those relationships with carers when you just can't see them face to face. So, we have seen an improvement in that, and it is easier now that some visitors can come in. But equally it used to be quite…. It used to be quite enlightening when you had more than the one visitor coming. Say, for example, you would maybe, have come, you know, you would maybe have, uhm, one daughter come in one day, a different daughter come in a different day, and each family member or each person who cares about that patient gives a little bit of the jigsaw.*
>
> *So, I felt that I had a better overview when I saw potentially multiple different people.*

Several professionals identified that there was an impact on physical ability caused by the absence of visiting and that this had a subsequent impact on the discharge options ultimately available. The impact on the ability to complete specific tasks necessary to move towards discharge was discussed by participants. Further to this, several professionals identified that the impact of restricted visiting was so detrimental to wellbeing that it was leading some patients to move towards end-of-life care, potentially prematurely. It was recognised that virtual visiting, including pet therapy and lunch clubs, could provide a limited substitute but that this option had substantial disadvantages for the autonomy and wellbeing of people living with dementia and their carers. Professionals recognised that virtual visiting prevented privacy and self-sufficiency and was not a substitute for face-to-face contact.

> *Specialist dementia nurse 3: Without any access to their loved ones, functionally, and sort of just the whole, you know, their whole well- being deteriorates. So, people have stopped eating and drinking, people have stopped wanting to get out of bed and people have expressed that they're given up and want to die.*
>
> *Specialist dementia nurse 3: People, you know, that [are} not able to come and see their relatives at the end of life, it's [tablets/laptops] been a good way of them to be able to, you know, have final messages and conversations and things like that, but you know that's not ideal.*
>
> *You know, you've got a 15-minute slot only. it's very difficult to leave somebody to have a private conversation.*

Carers also emphasised that the inability to visit complicated the discharge process thereby making it difficult to manage, particularly for carers unaccustomed to the hospital context, and not familiar with discharge. Being unable to physically meet with relatives living with dementia made complicated decision making, connected to discharge location, even more emotionally complex. For example, the absence of visiting meant that carers did not always know the physical and psychological condition of their relative, or whether they had deteriorated physically or cognitively. This reality meant that carers could be reluctant to accept the person living with dementia returning to their home, due to fears around a potential decline in abilities during the hospital stay. The logistics of aiding a relative, whilst being unable to visit them and assess their needs, was discussed at length by carers. The psychological pain of not being able to see a relative while they were at their most vulnerable in hospital, and potentially declining, was highlighted. Making decisions in relation to discharge to a care home setting was also made more complex by COVID 19 regulations (Department of Health and Social Care, 2020a), as carers had to tackle with the reality that they would not be able to visit their relative if discharged to a care home.

> *Carol: My mother in law was also worrying about the fact that she would have to do more around, the fact that she would have to do more hands-on care with my father-in-law, round personal care and stuff, until she was reassured that he was exactly able to do what he did before he went into hospital, so it's the fear of the unknown really and because I think he'd been in there for so many weeks. You don't know if she thought because, again, she couldn't be supported to do a zoom meeting and see him.*

There wasn't anything there, even a phone call for her.

Difficulties obtaining relevant information about any potential decline in the mobility or health of their relative on the ward made carers feel powerless during the planning of the discharge process. Some carers expressed their frustration trying to access information from the ward, due to the restrictiveness of COVID 19 measures.

Another problem was caused by the limited access to relatives in acute settings due to restricted visiting. Attending meetings to discuss discharge options was very difficult for carers, and involved isolating before the meeting, lateral flow tests, and meetings taking place in unusual locations, such as within cars within car parks. Carers also discussed their confusion during the discharge process around COVID 19 isolation requirements. One carer was able to compare the multiple opportunities to support the person living with dementia in the ward setting and communicate with health and social care professionals through visiting in the pre-pandemic era, with the dearth of opportunities for these actions during the pandemic.

> *Katie: I said it isn't happening. I'm having a meeting with my dad, sitting next to my dad, so I can support him, because he's told me repeatedly and I am only repeating what he's been telling me to tell you himself. And I said, I am not having that meeting without my dad being present, so you know what had to happen and what happened. The social worker met with me in the car park. I was told that I had to do my lateral flow in the car park when I arrived. I had to sit my dad in the front seat of my car, and I had to sit on a chair in the car park and the social worker had to sit on a chair in the car park. She had to have a meeting with us, with my dad, with the car door open.*

> *Elizabeth: I've got a friend, friends, so they're in their 80's. She's frail but independent, her husband's, you know, in hospital again during the pandemic. And you know she's been looking after him at home during the pandemic, with lots of different admissions along the way, and it's just what you said about people not being able to get through to the wards and the communications not been there.*

> *Whereas, you know in my time, I would turn up on the ward at eight o'clock in the morning and they would welcome me in and give me the spoon and say- 'here's breakfast'. You know, you could…. Thanks for doing it, sort of thing, you know, but I mean. It's completely different now.*

Carers were left feeling helpless and unable to assert any agency during the discharge process due to their almost complete exclusion from the ward setting during the pandemic era. This led to them feeling uniformed, uninvolved, and unprepared for discharge.

> *Jack: Bear in mind when my wife went in, she could walk, she could talk and she was only urinary incontinence. It then became a challenge over the two weeks to, which is the length of time she spent in, to get information. And I was never able to go and see her. I was very concerned about what was happening to her, the treatments she was having.*

It was apparent from the analysis that it wasn't just the absence of visiting, and face- to- face meetings with carers, that was causing a deficiency of agency for carers and people living with dementia, but also the inability for professionals to meet and take part in face-to-face discussions. It was evident that this was preventing adequate discharge planning. Professionals in the social care sphere commented that they believed less joint working occurred due to pandemic regulations (Department of Health and Social Care, 2020a). An inability to visit home environments, or to implement capacity assessments face- to- face, was also identified as limiting for professionals.

> *Specialist dementia nurse 2: And then if there's any, then if there's any ongoing issues and socially…. They would be referred to the social worker. The social worker used to sit in the meetings, but I don't think they are now doing because of COVID.*
>
> *Interviewer: Yeah, yeah, and is that to just reduce contacts. And is that the same with relatives, did they sometimes used to come [along]?*
>
> *Specialist dementia nurse 2: Yeah, yeah, they used to, but not so much now UNLESS it's really complex. And it needs to be more of a family case conference but that that used to happen quite regularly, that the family came in. But kind **of COVID**, that that's reduced a lot now, so it's done via phone calls.*

Professionals identified the discharge to assess model, implemented during the pandemic, as both a positive change to the discharge process and problematic. The discharge to assess model was praised for speeding up the discharge process to allow assessment to take place within the community. However, the funding available to facilitate the discharge was only for the first six weeks of the discharge period. This led to scenarios where individuals and families were content to be discharged with funding, but when obligated to pay for the packages of care after six weeks, experienced failed discharges and a return to the hospital setting. The ability of carers and people living with dementia to make the right decisions and choices, in relation to discharge destination, was hampered by the push to discharge to the community as quickly as possible during the pandemic era. This left limited time to consider all available discharge options potentially leading to the detriment of the carer and person living with dementia.

> *Social worker 01: And you know, people, like, people inevitably are quite willing to accept the support once, if they know that they're not having to pay for it. But then, once they have to pay for it, then that changes. Quite often, not in every case, yeah. Quite often that changes, and whether they need that support or not. If their incapacitated and they feel they can't pay that contribution, then they will withdraw and then inevitably they'll come back at some point in greater crisis.*
>
> *Specialist dementia nurse 3: Almost the opposite of what I've just said that the push to get people out may override people going to the best place for them.*

The data showed that carers believed that staff shortages during the pandemic were having a significant impact on the discharge process. This was supported by interviews with professionals who cited that the obligation for their colleagues and themselves to isolate was affecting patient wellbeing. Staff shortages creating problems in accessing community care packages were considered particularly challenging during this period. Professionals emphasised how shortages in materials, and equipment, were also impacting on discharge plans, and the ability of carers and people living with dementia to maintain choice and independence in the process.

> *Abdul: I've been in a scenario where they've got enough beds, but they haven't got enough staff, some staff are on annual leave, some are off sick, or the agency staff haven't turned up. And it's almost like one way to manage this is to release some of the patients. It's like when they, when you go to see mum on the ward and they're like, so your mom can go home and your like eh???*

> *Nobody told me that this morning, nobody told me that yesterday, nobody has rang me?*
>
> *Interviewer: And how has this affected staff with discharging and patients during COVID. Is it more difficult for you at the minute?*
>
> *Nurse 01: It can be to get, to get care packages, especially and I think this is because the community care is just stretched. So, you say, right, well, I need two carers for this person, four times a day. And then say okay, well, we can start, that in a week. And your like, well, that's a week that you've got this patient in hospital, who then can't go home.*

> *Consultant: Yeah, the other day in my rehab ward, the physio wanted to progress somebody onto a stick, but we were told there was a four-week waiting list to get a walking stick. Yes, and that's because of, there's been no mining over COVID of the raw materials. Then there's the shipping issues, the manufacturing issues, so there's significant pressures at the moment on equipment.*

Another significant issue preventing any meaningful agency, for people living with dementia during the pandemic, was the impact of PPE on their ability to understand and communicate with professionals. Carers with an insight into the communication difficulties experienced by their relatives were horrified at how difficult it must have been for their relatives to communicate with professionals wearing PPE.

> *Occupational therapist 01: I think, you know, somebody who, who's got a dementia and is confused, hospital is a confusing place anyway, and then not to see people's mouths and people's faces. And we just noticed that, you know, clients just tend to shut down a little bit and just it's too much hard work, so they'll just close their eyes and just shut down.*
>
> *Jack: I think it must have been horrific. I liken it to having been abducted by aliens and waking up on a spaceship and you've got all these strange people leaning over you, gowns on, visors on, wearing masks. And they're talking over you and it's probably muffled.*

The analysis showed that agency was curtailed significantly by the prioritisation of COVID 19 restrictions and regulations in the hospital setting during the pandemic (Department of Health and Social Care, 2020a), to the detriment of the person living with dementia and their carer. The inability of the person living with dementia or their carer to exert independence and agency within the discharge process, led to rushed discharges into the community setting following the discharge to assess model, which were hampered by the absence of face- to- face meetings, the inability to implement home visits or identify an appropriate care or nursing home. In summary, the barriers created by COVID 19 pandemic regulations made planning the discharge process very challenging and at times distressing, for professionals, carers and people living with dementia.

This section has outlined the findings of the analysis in relation to the importance of the ability of people living with dementia and their carers to maintain agency during the discharge process. The importance of supportive professionals, empowering processes and contexts that enable equality and risk taking were identified as supporting the maintenance of agency. In comparison, the ability of bureaucracy, medication, and the day of discharge to undermine agency during the discharge process was considered.

In the next section, I will outline the final section of the findings which utilises the Appreciative Inquiry process further, and asked the participants to Dream about the changes they believe would be beneficial for ensuring the wellbeing of people living with dementia and their carers. Carers and health and social care professionals are ideally placed to consider what changes to the process would enable wellbeing to be supported for this population due to their insights into the discharge process, and their understanding of wellbeing within this context.

Chapter 9. Dream

9.1 Introduction to Dream findings

This section summarises the specific changes that carers and professionals identified as being potentially beneficial to the discharge process, and which emerged during the Dream section of the Appreciative Inquiry analysis process. This aspect of the process moves away from focusing on the strengths and weaknesses of the discharge process to instead identify potential improvements. There are areas of overlap with other sections of the analysis, but it is important to the Appreciative Inquiry method to outline the specific changes, or dreams, that carers and health and social care professionals identified as desirable.

Carer and professional opinions were divergent, with carers having a much more detailed insight into the changes required to support wellbeing for both the carer and person living with dementia. Professionals often focused on changes that would be beneficial to their professional role such as improving paperwork processes. Carers had insight into wider changes that might be required in relation to the need for a national standardized system, with accountability for the discharge process, and the changes needed to support wellbeing for the carer and person living with dementia. Table 18 identifies the changes required to the hospital discharge processes noted by professionals and carers.

Table 18. Dream. Required changes to the hospital discharge processes identified by professionals and carers.

Table 18	
Professionals	**Carers**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in	Extensive explanation of the discharge process, including

relation to the availability of a social worker	transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options
Additional care package availability in community, including additional support systems	Adequate signposting
	Further holistic involvement in the discharge process, including being given choices
Changes beneficial to the person living with dementia and their carer:	Further respite availability factored into discharge process
Further focus on the wellbeing of carers and people living with dementia	Meaningful communication replacing platitudes and inclusion of communication tools
Removal of stigma and discrimination from discharge process	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

9.2 Findings from Dream analysis

Professionals highlighted several changes they thought would be beneficial to the discharge process. They felt that further focus was required on the wellbeing of both parties, and the presence of additional adequate care and support systems in the community to facilitate this was important.

> *Interviewer: And what, what do you think, when you, when you are planning the discharge, what are the things that kind of help it to go well and to help it to be a positive discharge?*
>
> *Specialist Dementia Nurse 2: Making sure that the carers are getting the right level of support, because carer support are really good at knowing what's available on the ground, what services are out there and connecting with the carers.*

Professionals felt that often there was a rush into care packages or placements at discharge based on stigma and discrimination, concerning the physical and mental abilities of the person living with dementia, instead of holistically assessing the person living with dementia and enabling some agency and choice. Further to this, professionals expressed frustration at the limited care packages and support mechanisms in place in the community setting and felt that this context caused complications and delays in the discharge process.

> *Specialist Dementia Nurse 03: When people have got a dementia diagnosis, there is still that stigma there.*
>
> *Consultant 01: And they, they don't know why and sometimes that does happen and often with it on our ward, and it's because packages of care haven't come through.*

Carers agreed that there is a need for more support systems to be available to carers in the community, but their focus was for the provision of appropriate respite services primarily. Many carers discussed a need for more respite to be available, and for this to be factored into the discharge planning process.

> *Jack: So, I’m very fortunate that I made a connection with this carer, and been able to get somebody who can work more flexibly, and casually, and regularly, and just kind of come to an agreement with me, when I need them and, but I do wish that carers organizations had a pool of carers, paid carriers that you could book as and when required.*

Health and social care professionals also felt that some changes in the paperwork, and interprofessional communication, would lead to the improvement of the process.

> *Social Worker 01: I think, better communication between the health and social care. I mean, that that can always be improved in every situation.*

A ward based social worker was requested as professionals cited that some difficulties arranging discharges were due to limited communication with the social work team. Most professionals did not comment at length on what they felt could be better about the discharge process or appear to have a significant perception into what could be better for the carer, and person living with dementia. This was disappointing but one professional had some insight into a potential explanation for this, citing the pressures of the workplace leaving little time for professional reflection, in the context of significant funding pressures.

> *Nurse 01: Maybe have a ward based social worker, that you could go speak to, we're quite lucky in the fact that our physios and OTs are around. To get hold of the social workers, it's sometimes quite difficult.*
>
> *Social Worker 01: I think, sometimes, we can get a little bit blinkered and say well, you know, we’re supporting with personal care, we're doing this, we're doing that, but actually the person is saying, but I'm not getting out as much as I, as I need to. We're not responsive to that, and that's because of the pressures, funding resource pressures. Obviously, it's limited, in what we can provide.*

Carers discussed changes they would welcome and that they believed would support their wellbeing, and the wellbeing of the person living with dementia, in much greater detail than professionals. On numerous occasions carers mentioned that they required someone to explain the discharge process to them and help them to understand the care and hospital system. The financial implications of the discharge process were also mentioned several times by carers. It was discussed that no-one had taken the time to explain the financial aspect of the discharge process, even though the financial implications of different discharge options are significant.

> *Michael: They're not going to do anything for me, you know, I think that what I would say is that, you know, somebody needs to make people aware of what the options are. And what are the financial support services available. And those sorts of things, because people just have to find their own way, through it.*

Understanding relevant professional roles, and what the process of discharge involves was something carers identified would be valued highly. More detailed signposting was also mentioned numerous times, with carers complaining that although certain services or modes of communication existed, they were of limited utility if they were not signposted to them effectively. The importance of meaningful communication was also mentioned numerous times, with carers decrying the platitudes often communicated via telephone. Carers demanded more analytical information be provided about the person with dementia’s physical and mental wellbeing, rather than the standard response of ‘slept well overnight, sat eating breakfast.’ There was also the request for more pro-active communication from professionals.

> *Carol: Uh, as far as speaking to him individually, again, until we got the number of a phone that could contact someone who knew him, uhm, you were only left asking somebody who would say, ‘oh yeah he’s fine, he’s sleeping at the moment’.*
>
> *Elizabeth: And nobody tells you what your options are, you know when you're booking transport, they don't say to you. No one says to take your own wheelchair into hospital is the most streamlined, well the most streamlined is to drive yourself to hospital with a blue badge, in a wheelchair accessible vehicle, but yes, it takes a while to work transport out, that sort of thing.*

Timings and the transport options were mentioned on several occasions as areas not explained well and causing significant stress on the day of discharge. More communication about the arrangements for the patient to come home was requested. Ensuring that the carer was adequately involved in the discharge planning process, and better education for health and social care professionals in relation to caring for a person living with dementia, were discussed as changes that needed implementing to ensure wellbeing. Being given choice around the discharge process, and tools to allow for adequate communication were requested. Several carers noticed that health and social care professionals sometimes did not have the skills or education needed to organise an appropriate hospital discharge for people living with dementia and their carer.

> *Jack: The discharge, right. I think, first of all, I should have been more involved in, in the timings etc, you could call or certainly, I should have been given, if you like better notification. Now, a simple thing would have been a telephone call to say your wife is getting into an ambulance in the next half an hour, not much simpler than that. Even a text message.*
>
> *Amy: First of all, I think someone should have come out and had a look at the house. And told me what needed to be moved to make things safer and talked to me about the realities of people coming out of hospital. I should have been given the opportunity to choose for my mother to go to respite before coming home and it was never even suggested. And I think they should have taken me into account and the whole situation and looked at who was caring for my mother and what would the pressures be on me.*

Carers identified that a change in the way discharge was assessed was required. Carers noted the difference in abilities and needs between a person living with dementia still in hospital and after discharge home. Carers requested that the discharge assessment should be ongoing, with vital assessments taking place in the home setting, rather than the hospital context. This occurred under the discharge to assess model implemented in response to COVID 19. More specialist dementia nurses were requested by carers due to their skill and insight into the challenges faced by the person living with dementia and their carer. A more holistic discharge system that took carer needs into account, and actively sought to include them in the process was requested by several carers.

> *Amy: It has been difficult. Individuals that I've dealt with have been really, really helpful and supportive. So, it's not the individuals, it's the system that's in place. It's not the people because when the physio comes out, they are really helpful. You*

> *know, they brought her a cup of tea and a wheeled trolley and sorted out an additional Zimmer for upstairs. Things like this, so, when they come they do get things done and but it's like the system, not individuals and that's the management isn't it*
>
> *It's a holistic approach that's needed isn't it.*

Several carers mentioned that they felt the discharge system needed radical overhaul. It was mentioned that policies and procedures needed to be put in place that centralised the needs of the carer, and the person living with dementia at the heart of the process, with some legislation in place to ensure accountability if this was not achieved. One carer felt that there should be a universal gold standard process developed, that all NHS trusts should adhere to, to ensure both quality and consistency within the discharge process. Carers were often shocked that there wasn't an explicit national framework for the discharge process for this patient and carer group, with an accompanying standardised set of operations.

> *Shelly: If I was diagnosed with cancer I would have a full team, I would have a Macmillan nurse. I would have a named nurse at the hospital. I would, you know, and it needs to be recognised as a terminal illness.*
>
> *That's what I'm trying to say.*
>
> *It isn't. It's how do we live with cancer, well, x y and Z.*
>
> *So how do we all live with dementia? Where's the policies, where's the protocols?*
>
> *There isn't any.*

It was evident from the Appreciative Inquiry analysis process, that there are numerous potential alterations to the discharge process that could be made to support the wellbeing of people living with dementia and their carers. Carers and professionals were united in their belief that more should be done to ensure wellbeing during the hospital discharge process. This included: more support for carers around finance and assessments; explanation in relation to transport; better communication; availability of policies and procedures; being adequately involved in the discharge process; being given choices; the presence of more speciality dementia nurses; and a more holistically focused process that values the needs of carers as well as people living with dementia. The impact of the Appreciative Inquiry process on data collection and analysis, facilitated the incorporation of the opinions of carers; and health and social care professionals, directly into the findings in regard to improvements to the process. The dream stage of the Appreciative Inquiry method lays the groundwork for the next stage of design, which aims to identify achievable changes to the process.

The findings have shown that there are many aspects to the subjective concept of wellbeing, but that supporting hope, personal worth and agency, are vital to maintaining the wellbeing of both the person living with dementia and their carer during the hospital discharge. I will now address how the analysis of the empirical data address's objective 2: identifying factors (environmental, organizational, resource or social) that ensure the physical, emotional and social wellbeing of patients living with dementia and their carers.

9.3 Factors that ensure the wellbeing of people living with dementia and their carers

The analysis has demonstrated the key factors that ensure the wellbeing of carers and people with dementia during the discharge process:

- **Proactive health and social care professionals and empowering processes that support carers and people living with dementia.**
- **Contexts that are supportive financially and in relation to care availability, and which encourage and allow for risk taking alongside consideration of physical needs.**
- **Consideration of needs beyond the physical, alongside person centred care that acknowledges the carer as a care partner and considers their needs.**

Additionally, cross-cutting features including **adequate communication and planning, appropriate safeguarding; limited bureaucracy, freedom from discrimination, transparent medication processes, and an appropriate day of discharge itself** are important factors that help to ensure the wellbeing of people living with dementia and their carers.

These findings help to develop the requirements specified, but not delineated, in the policy guidance outlined in chapter 3 (National Institute for Health and Care Excellence, 2015). These include the requirement detailed in section 1.5.15 that ‘the discharge plan takes account of the person's social and emotional wellbeing, as well as the practicalities of daily living’ (National Institute for Health and Care Excellence, 2015).

In the next chapter, the findings from the systematic review and empirical analysis will be integrated. The development of a framework generated from the findings to ensure the wellbeing of this carer dyad during the hospital discharge process will be presented.

Chapter 10. Integration of systematic review findings with empirical findings

10.1 Introduction to integration of findings

In this chapter I will integrate the findings from the systematic review analysis with the findings of the empirical study. I will discuss how the integrated findings have been used to begin the development of a framework aimed at ensuring the wellbeing of people living with dementia, and their carers, during the discharge process. By doing so, I will address the primary aim of the study and the first part of the secondary aim to expand the evidence base available to clinicians and policy makers in relation to this topic, and patient -carer dyad. The final section of this chapter will identify the relationship between findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data analysis and the systematic review synthesis.

The aim of this research was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. A secondary aim of the research included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group, during the hospital discharge process in the post COVID 19 climate.

The systematic review and empirical study were conducted separately but it is a useful exercise to consider how the two relate to each other. It is important to identify how the findings from the empirical project compliment or contradict the established literature in this area to demonstrate the value of this research project, and its addition to the evidence base available. This comparison of the findings of the systematic review and the empirical analysis was completed inductively by noting where the findings of the two research streams were cohesive, and where the findings diverged. The topic of wellbeing did not feature within the systematic review synthesis of the experience of people living with dementia and their carers, nor did the pandemic, and therefore, there is significant divergence between the systematic review synthesis, and the analysis of the empirical data which aimed to address this gap in the literature. Figure 10 depicts the development of the pandemic alongside my research project.

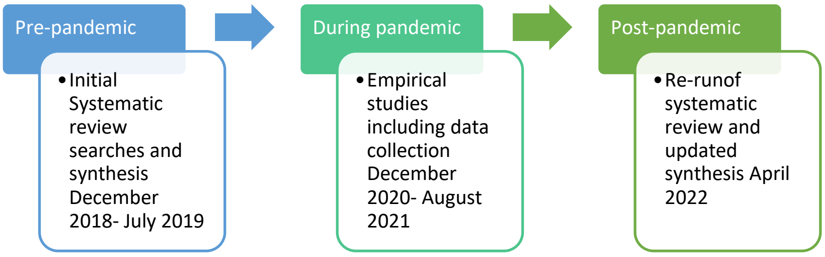


Figure 10 Pandemic timeline

I will identify how the empirical findings address some of the gaps apparent in the evidence base for this topic as revealed by the systematic review findings. I will argue that the findings of both the systematic review and the empirical study add to the wider body of evidence regarding the hospital discharge process for this group, and the topic of wellbeing.

The qualitative systematic review (outlined in chapter 2) aimed to answer the question: What are the experiences of people living with dementia and their carers, during the hospital discharge planning process? I utilised a meta ethnography method to synthesis the 36 studies that related to the carer experience and the 26 studies relating to patient experience following the re-run of the searches in 2022 (please see chapter 2 for further details). The findings from the synthesis for patients and carers are summarised in table 19 below.

Table 19. Systematic review themes relating to the synthesis of the experience of people living with dementia and their carers during the hospital discharge process.

Table 19
Systematic review themes relating to the synthesis of the experience of people living with dementia during the hospital discharge process
Theme 1: Patient undermined from taking part in discharge planning and decision making
Subtheme: Family members replacing patient in the discharge decision making process
Subtheme: Hospital system undermining ability of patient to have agency during the discharge process
Subtheme: Health and social care staff member's actions preventing patient involvement in the discharge process
Theme 2: Privileging of hospital requirements above patient centred care
Subtheme: Rushed discharge processes due to hospital requirements
Subtheme: Unsafe discharge practices due to hospital pressures
Theme 3: Absence of resource, policy and governance in the hospital discharge process
Subtheme: Deficiency in availability of community services
Subtheme: Lack of adopted discharge policy initiatives alongside ad hoc discharge planning
Systematic review themes relating to the synthesis of the experience of carers during the hospital discharge process
Theme 1: Carer experience of being included in the discharge process
Subtheme: Experience of being included in the discharge planning process (positive aspects)
Subtheme: Experience of being included in the discharge planning process (negative aspects)
Theme 2: Carers experience of being excluded from the discharge planning process
Subtheme: Not being treated as an expert in the care of the person living with dementia
Subtheme: Recipient of ineffective communication
Theme 3: Requirement for further robust support during discharge process

Subtheme: Unmet need for support for carer navigating the discharge process

10.2 Gaps revealed by the systematic review.

The systematic review revealed there was limited evidence on the following:

- Identification of how positive experiences of hospital discharge can be facilitated.
- How wellbeing can be supported in the discharge process.
- Identification of mechanisms to improve the hospital discharge process.

These research gaps informed the protocols for the empirical work and specifically, the topic guides for interviews. The topic guides for carer interviews sought to uncover the support carers identified as enabling the maintenance of wellbeing, elements of the discharge process that carers identified as functioning well and areas requiring improvement. The interview data, therefore, compliments the key findings of the systematic review to provide a more complete picture of the hospital discharge process. The decision to use an Appreciative Inquiry approach (Watkins, Dewar and Kennedy, 2016) facilitated this need to focus on positive experiences of the hospital discharge process which enable wellbeing.

Table 20 summarises the main areas of cohesion between the findings of the systematic review and the empirical study. Areas of divergence caused by the pandemic are also identified. The empirical data reflected many of key themes evident in the systematic review synthesis. The empirical study did not include patient participants due to the impact of social distancing and therefore, some of the nuances of the patient synthesis are not reflected in the empirical data. Several areas of disagreement emerged from the comparison of the systematic review synthesis and the empirical analysis. These included the value of formal discharge meetings, whether collaboration between professionals and carers is increased if there is a care home destination discharge and the status conferred on carers holding power of attorney. Table 20 details where the empirical data aligned with or diverged from the findings of the systematic review. Column A of Table 20 outlines the findings from the systematic review synthesis and column B identifies where these findings coincide or diverge from the findings of the analysis of the carer and professional empirical data.

10.3 Outlining cohesion between systematic review findings and empirical data findings and divergence caused by the pandemic.

Table 20. Cohesion between systematic review synthesis and empirical study findings.

Table 20	
Systematic review finding	**Empirical data finding**
1 Exclusion from discharge process for carer (Theme 1 in carer synthesis: *Experience of being excluded from the discharge planning process*) (Cox, 1996)	1 Identified within the subtheme *empowering or disempowering process of planning the discharge process* (Agency) Carers identified that they were not involved in discharge planning.
2 Lack of adopted discharge policy initiatives alongside ad hoc discharge planning (Theme 3 in patient synthesis: *lack of adopted discharge policy initiatives alongside ad hoc discharge planning*) (Coleman and Roman, 2015)	2 Identified within the subtheme *empowering or disempowering process of planning the discharge process* (Agency) Carers did not believe that adequate discharge planning was occurring.
3 Absence of Safeguarding (Theme 3 in patient synthesis: *lack of adopted discharge policy initiatives alongside ad hoc discharge planning)* (Bauer, Fitzgerald and Koch, 2011; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016)	3 Identified within subtheme: *Safeguarding as a pillar of person-centred care* (Personal Worth) The carer was distressed at lack of care shown to relative who was sent home unexpectedly in an ambulance.
4 The undermining of involvement in the discharge process from health and social care professionals and the	4 Identified within subtheme: *Supportive professionals enabling empowerment* (Agency)

hospital system itself *Experience of being excluded from the discharge planning process* (Theme 3 Carer synthesis) (Emmett *et al.*, 2014; Poole *et al.*, 2014; Telford, 2015)	Carers often felt undermined by actions of Health and Social Care Professionals.
5 Lack of clarity related to discharge process/policy (Theme 2 in carer synthesis: *Recipient of ineffective communication*) (Huby *et al,* 2004; Emmett *et al,* 2014; Kable *et al,* 2015)	5 This was evident within the analysis but tended to be conflated by participants with the *Uncertainty caused by the COVID 19 pandemic in the discharge process preventing hope* (Hope) and is identified within that subtheme.
6 Rushed discharge process (Theme 2 carer synthesis: *Unmet need for support for carer navigating the discharge process*) (Kaiser and Varghese, 2014),	6 Rushed discharge process were identified within the data but often associated with the pandemic and guidance to discharge quickly as identified within *COVID 19 and the prevention of agency* (Agency).
7 Inadequate community provision (Theme 3 in patient synthesis: *Deficiency in availability of community services*)	7 Carers and professionals identified inadequate community provision, but this was conflated with the impact of the pandemic and identified within subtheme: *Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope* (Hope).
8 Difficulty navigating community services (Theme 3 carer synthesis: *Complexity of navigating community services)* (Jamieson *et al.*, 2016; Gilmore-Bykovskyi, 2017)	8 Identified in the analysis by both Health and Social Care Professional participants but conflated with the impact of the pandemic: *Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope* (Hope).
9 Ineffective communication (Theme 3 carer synthesis: *Recipient of ineffective communication*) (Bauer *et al*., 2011; Fitzgerald *et al.*,	9 Identified within the subtheme *Communication* (Personal Worth). Carers identified the impact of poor communication.

2011; Emmett *et al*., 2014 Sewter, 2014)	
10 Medication issues (Theme 3 carer synthesis: *Lack of adopted discharge policy initiatives alongside ad hoc discharge planning)* (Jamieson *et al*., 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017)	10 Identified within subtheme *Medication as a potentially disempowering factor in the discharge process* (Agency).
11 Prioritisation of risk (Theme 3 carer synthesis: *Hospital system undermining ability of patient to have agency during the discharge process*. (Kadushin and Kulys, 1994; Mockford et al., 2017)	11 Identified within subtheme *Contexts that enable equality and risk taking* (Agency). It was evident that risk concerns were prioritised in the pandemic context.

Many of the issues identified from the qualitative synthesis were echoed in the findings from the empirical data. For example, the analytical finding from the empirical data that wellbeing is not prioritised for carers and people living with dementia during the discharge process agrees with the systematic review synthesis outlined in chapter 2 (Cumbler, Carter and Kutner, 2008; Bauer, Fitzgerald and Koch, 2011; Kable *et al.*, 2015; Deeks *et al.*, 2016).

Within the analysis of the empirical data, it was apparent that carers and people living with dementia continued to have the negative experiences identified in the systematic review. These experiences included being excluded from the discharge process (Cox, 1996), perceived ad hoc or absent discharge planning (Coleman and Roman, 2015), at times a lack of safeguarding (Bauer, Fitzgerald and Koch, 2011; Parliamentary Health Service Ombudsman, 2016; Macmillan, 2016), the undermining of involvement in the discharge process from health and social care professionals and the hospital system itself (Emmett et al., 2013; Poole et al., 2014; Telford, 2015), a dearth of clarity in the discharge policy and process, rushed discharge processes (Kaiser and Varghese, 2014), inadequate community provision and the inability to involve the person with dementia within the discharge process.

10.4 Identifying the role of the pandemic in the divergence between the synthesis and empirical data interpretation.

Difficulty navigating community services (Shippen, Young and Woods, 2011; Gilmore-Bykovskyi, 2017), ineffective communication and issues in relation to medication at discharge were all apparent in the empirical data in cohesion with the findings of the systematic review (Cumbler, Carter and Kutner, 2008; Kaiser and Kaiser, 2017). The impact of the pandemic in exacerbating these issues due to limited face- to- face contact was noted. The empirical data analysis also identified noted exceptions to these findings in agreement with the findings of the systematic review. These included that good discharge planning, which involves excellent communication, can enable a positive experience, leaving carers feeling that they were treated as care partners (Gupta *et al.*, 2006; Rhynas *et al.*, 2018).

The systematic review also revealed how ‘risk’ was often prioritised by professionals above the person living with dementia and their carer’s need for agency and choice (Norman, 2003; Huby *et al.*, 2004; Redwood, Eley and Gaughan, 2016). This identified finding played out during the pandemic in relation to infection control measures being consistently prioritised above maintaining wellbeing. From the analysis of the empirical data of this study, it is shown that rushed discharges due to hospital pressures were a feature of the early pandemic experience for people living with dementia and their carers. The subtheme identified in the third theme of the systematic review synthesis for carers of people living with dementia was overtly apparent during the pandemic period (complexity of navigating community services). The deficiency in community services became an absence of community services, as almost all were suspended for long periods during the pandemic, and being discharged without a discharge plan became standardised with the ‘discharge to assess’ model (Department of Health and Social Care, 2020b) formalised during the pandemic.

Many of the publications included in the systematic review addressing patient and carer experiences of the discharge process, focused on inclusion or exclusion in the planning process of people living with dementia and their carers (Cox, 1996). During the pandemic, this became almost a moot point due to the impact of social distancing and therefore, this finding is not reflected heavily in the empirical analysis of this research project. Although the absence of discharge planning was present within the empirical data, it was somewhat obscured by the wider impact of the pandemic. The discharge process during the pandemic was fundamentally dictated by social distancing policy decisions and face- to- face meetings, visitors to the ward, and other contacts were not allowed. Therefore, it was difficult for carers or people living with dementia to be truly involved in planning the discharge process (Department of Health and Social Care, 2020a). A rushed discharge process with hospital needs being placed above patient and carer wellbeing was prevalent during the COVID 19 pandemic. Safety and risk in relation to infection control were definitively placed above carer and patient needs according to the narratives within the empirical data of this research project. The analysis of the empirical data revealed that pandemic policy largely exacerbated problems already present within the discharge process as identified in the systematic review synthesis.

10.4.1 Divergence between the findings of the synthesis and the empirical analysis.

The systematic review synthesis demonstrated the value of formal discharge meetings (Cox, 1996; Gupta *et al*., 2006; Rhynas *et al*., 2018). Carers identified that formal meetings granted the opportunity for their opinions to be heard and to enable their involvement within the discharge process. However, the analysis of the empirical data revealed a mixed experience of discharge meeting for participants. Some experienced supportive discharge meetings which treated the carer as a care partner and others felt undermined by the meetings. This suggests that the value of discharge meetings may be fluctuating in different contexts. Cox (1996) and Telford (2015) identified that collaboration between professionals and carers increased if there was a care home destination discharge. The analysis showed that carers did not believe this to be true within the empirical data and that discharge destination made no difference to the interaction between carers and health and social care professionals. Coleman and Roman (2015) identified that there was a higher status conferred on carers holding power of attorney, but this was also not reflected within the analysis of the empirical data. Carer participants did not feel that there was any benefit bestowed on them through power of attorney and even felt this was at times ignored.

An area highlighted in the analysis of carer data but not prevalent in the systematic review findings was the importance of clarity regarding financial matters. In the analysis, carers frequently identified accessing finance overly bureaucratic and a source of stress, and yet this finding was not heavily reflected in the systematic review synthesis. The limited consideration of wellbeing in previous studies could explain why financial concerns have not been addressed within the research process. Processes were identified as a particular issue within the data of this study, more so than in previous research where involvement in decision making has often been ubiquitous. This may be due to the more prevalent role of processes during the pandemic period. In the empirical data it was evident that communication regarding the discharge was often curtailed to telephone contact, but this was expected during the pandemic. Therefore, while the communication by health and social care professionals was criticised, it was criticised less so than discharge planning. This may be because planning was identified as more important in pandemic conditions where opportunities to communicate were limited. Person centred care was not mentioned as frequently as would be expected in the empirical data but this may also be due to the limited opportunities to practice person centred care during the pandemic.

The empirical project focused on the topic of wellbeing and, in cohesion with the Appreciative Inquiry approach, aimed to identify ways in which wellbeing is, or can be supported within the discharge process. The empirical data analysis also aimed to identify the nuances of the factors that impact on the wellbeing of people living with dementia and their carers. This was not the focus or approach of the research included in the systematic review which was often aiming to identify problematic aspects of the discharge process. This may explain some of the differences between the synthesis of the systematic review data and the empirical data. The empirical analysis focused on where wellbeing is or could be supported within the discharge process, whereas the systematic review data was frequently focused on identifying negative experiences of the discharge process and areas for improvement.

As previously mentioned in the systematic review chapter (2), the review synthesis did not identify qualitative data relating to considerations of wellbeing specifically during the discharge process in the 2018 search. The 2022 search also did not highlight any research specifically focused on wellbeing for this patient and carer group during the hospital discharge process. Therefore, as previously identified it is possible that this is the only study that focuses on this topic during the pandemic. It is, therefore, an important addition to the evidence base in relation to wellbeing for this carer dyad during the hospital discharge process. The re-run of the searches in 2022 did not highlight any qualitative pandemic data regarding the experiences of carers or people living with dementia of the discharge process. Therefore, the findings of the empirical analysis represent an important source of in-depth data in relation to the qualitative experiences of this demographic during the pandemic. Research was implemented which examined the qualitative experience of wellbeing (Hanna *et al.*, 2022) for this patient carer dyad during this period, but without a specific focus on the discharge process.

This section has compared the areas of correlation and contention between the findings of the systematic review synthesis and the findings of the empirical data analysis. I have also identified areas where there is divergence due to the impact of the pandemic. In the next section of this chapter, I will outline the development of a framework to ensure wellbeing in the post pandemic period in answer to objective 5.

10.5 Framework to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Objective 5: Develop a framework, based on the perspectives of carers and healthcare professionals to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Previously in this chapter, it was identified that there is limited evidence available in relation to wellbeing. Therefore, a framework focused on ensuring wellbeing during the discharge process, for both carers and people living with dementia, will have utility in the post pandemic period. Due to the diversity of experience, such a framework would need to be flexible and accommodating to both people living with dementia and their carers. Research by Ashbourne *et al.* (2021) has developed a theoretical framework for dementia-specific care transitions. This work expanded on the frameworks developed by both Naylor and Van Cleave (2010) and Hirschman *et al.* (2015) in relation to transitions of care. None of these models are focused specifically on hospital transitions, nor the maintenance of wellbeing during this period of the dementia journey. Therefore, the framework presented here enables the consideration of wellbeing to be considered alongside more functional frameworks.

Figure 11 represents a potential framework based on the findings of this research project. It has been designed in accordance with the socially constructed nature of wellbeing and the discharge process to enable flexibility and consideration of individual requirements. Although numbered 1-6, none of the areas take precedence over another. The numeration is designed to aid discussion and clarity of the framework. The findings from the Dream section of the analysis, developed through the application of the Appreciative Inquiry method were utilised in designing this framework. The findings from both the empirical analysis and review synthesis were also incorporated. The framework is not designed to be prescriptive but to provide guidance to professionals and policy makers about the key areas that professionals and carers identified as requiring reformulation to ensure wellbeing. Areas 1, 3, 4, 5, and 6 all align with recommendations in the policy outlined in chapter 3 (National Institute for Health and Care Excellence, 2015: Social Care Institute for Excellence, 2022). The next section of this chapter will now consider each of the areas of the framework. Carer and health and social care professional data was not always equivalent. Therefore, there are deviances in the findings across the analysis. The similarities and deviances are identified in table 22.

Table 21 represents the findings of the Dream section of the analysis and identifies the key areas professionals and carers would like to see change within the discharge process to enable the wellbeing of people living with dementia and their carers.

10.6 Dream analysis findings.

Table 21 demonstrates how the key findings from the Dream section of the empirical analysis relates to the framework. This section represents the ‘design’ phase of the Appreciative Inquiry cycle. Figure 11 depicts the potential wellbeing framework for people living with dementia and their carers during the hospital discharge process.

Table 21. Findings from Dream analysis.

Table 21	
Professionals	**Carers**
More focus on the wellbeing of carers and people living with dementia (1)	Further respite availability factored into discharge process (5)
Additional care packages availability in community including additional support systems (5)	Explanation of the discharge process including transport options and medication (3)
Removal of stigma and discrimination from discharge process (4)	Explanation of the financial implications of different discharge process options (3)
Paperwork improvement (3)	More signposting (3)
Improved interprofessional communication particularly availability of social worker (5)	Meaningful communication replacing platitudes and inclusion of communication tools (4)
Discharge assessment process to be community based (5)	Further holistic involvement in the discharge process including being given choices (2)
Greater tolerance of risk (2)	Further education in relation to dementia for health and social care professionals (6)
Requirement for process to place needs of carer and person living with dementia centrally (6)	Discharge assessment process to be community based (5)

	More specialist dementia nurses to be available during the discharge (5)
	A national standard and procedure for discharge with accountability (5)
	Carers to be listened to more (6)

Figure 11. Wellbeing framework

Each area has been mapped to the finding it represents. The areas included in figure 11 are outlined here.

1 Wellbeing as primary concern of discharge process that moves beyond only physical preoccupations.

This change will enable a holistic definition of wellbeing to take a central role. This is particularly important in relation to people living with dementia where research shows that physical wellbeing concerns can dominate discharge decision making (Emmett *et al.*, 2013). The analysis showed that concerns relating to physical safety could undermine other wellbeing areas, for example, requirement for respite. This requirement is identified in the available policy documentation (National Institute for Health and Care Excellence, 2016) but does not appear to be consistent within the discharge process.

2 Tolerance of risk in discharge planning

This will enable both carers and professionals and people living with dementia, to make decisions that enable wellbeing and tolerate risk. This change was requested by both groups of participants within the analysis.

3 Clear Road map for carer of discharge process (transparent processes)

Carers requested further transparent processes, as did professionals, particularly around social service input, and the day of discharge. The empirical data showed a requirement for further clarity for carers around areas such as transport home, medication, financial considerations, and the day of discharge processes. This level of planning is recommended by the policy discussed in chapter 3 (National Institute for Health and Care Excellence, 2015), but does not appear to be currently present in the process.

4 Carer and person with dementia as care partner with health and social care professionals

Meaningful communication, decision making, and the removal of stigma and discrimination were identified as vital to ensuring wellbeing within the empirical data.

5 Identification of adequate resources for carers and people living with dementia (accountability)

The need for adequate respite, the involvement of specialist professionals, care package availability and community re-assessment were all identified as vital to wellbeing. Carers requested more specialised nurse involvement and a national standardised discharge process (policy focused).

6 Centralisation of carer and person living with dementia in process from admission to discharge

Professionals ensuring that carers and people living with dementia are centralised in the process should be a priority. Carers requested adequate signposting and consideration of patient carer dyad needs.

In the next section, I will demonstrate in a table format the relationship between the systematic review synthesis findings, the empirical analysis findings, and the Appreciative Inquiry dream analysis findings.

10.7 How the findings from the empirical data and systematic review synthesis support the wellbeing framework.

This section of the chapter will demonstrate the configuration of the findings across the research project entire. This table incorporates the findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data and systematic review. Table 22 demonstrates that there is support for the tenets of the wellbeing framework across all areas of the analysis.

Table 22. Cohesion across the findings of the systematic review and empirical data.

Table 22			
Dream Framework area	**Findings from professional interviews**	**Findings from carer interviews**	**Findings from systematic review**
1 Wellbeing as primary concern	Identified need for more focus required on the wellbeing of carers and people living with dementia	Identified a requirement for further focus on carer wellbeing and the wellbeing of people living with dementia. Move away from process centred discharge	Wellbeing is not the primary concern of the discharge process. Hospital processes and risk assessments often centralised.
2 Tolerance of risk	Some professionals supported	Further holistic involvement in the discharge	Concerns regarding risk often

	further tolerance of risk, but some did not	process including being given choices that include risk	prioritised above other areas
3 Road map for carer of discharge process (transparent processes)	Requested improvements in paperwork. Further clarity in relation to day of discharge and social service availability.	Further clarity required around transport home, medication, financial considerations and day of discharge processes	Further support required by carers navigating the discharge process
4 Carer and person living with dementia as care partner	Removal of stigma in decision making	Identified requirement for more communication and shared decision making	Requirement for more communication and signposting
5 Identification of adequate resources for carers and people living with dementia	More resource availability in community. Further interprofessional communication with social worker.	Further specialist nurse involvement, standardised discharge policy	Requirement for adequate community resources. Carers often facing long waiting times or absent services
6 Centralisation of carer and person living with dementia in the process from admission to discharge	Process to be driven by carer and patient needs and not hospital concerns	Carers to be listened to more within discharge process	Being involved in decision making

Table 22 reveals the detail of how the wellbeing framework is supported by the findings across the research project. Although there is diversion in specific detail, there is cohesion in each section of the wellbeing framework. Each section of Table 22 illustrates how the framework is supported by the empirical analysis findings and the systematic review synthesis. In the next section, I will consider the utility of the wellbeing framework further, and the value it may offer in re-focusing the discharge process onto the topic of wellbeing. I will also consider the relationship of the framework to available policy.

10.8 Discussion of the wellbeing framework for people living with dementia and their carers during the discharge process.

The framework represents a significant change in relation to the primary language utilised during the discharge process. In a previous section of this chapter, it was mentioned that a significant transformation in language usage and discharge focus is required to enable a shift towards wellbeing as a priority. This shall now be developed further. Person centred care has been the dominant term for care which is holistic and individualised, and is considered the gold standard in dementia care. However, since its inception, it has been identified that 'person-centred care' lacks clarity and definition in terms of clinical practice and is often not being implemented effectively (Edvardsson, Winblad and Sandman, 2008; Clissett *et al.*, 2013). Although the seminal work by Kitwood (1997) has immense value and was revolutionary in transforming how people living with dementia are conceptualised and treated, the term person centred care has arguably never had a precise meaning within the sphere of clinical practice. This has limited its impact and obscured its true purpose and meaning. Certainly, many of the participants of this study were not experiencing 'person centred care', even if that term was frequently being utilised in interviews with professional participants.

It could be contended that the word *care* itself shifts the focus towards the idea of physical 'care' within the discharge process. This is misleading and tends to mean that carer needs are overlooked. In contrast, wellbeing as a new concept can be defined by carers and people living with dementia themselves. It has the capacity to operate as a much broader term which enables it to be individualised to encompass many different social, physical, emotional, and economic areas. A shift in terminology, while challenging to introduce in practice, would not be impossible and there are historical examples where this has been successful, including the classic example offered by person- centred care itself (Kitwood, 1997). Such a shift in language offers the opportunity for a different outlook on the discharge process for carers, people living with dementia, and health and social care professionals. Person-centred care should remain an important concept within the discharge process due to its emphasis on the person, as in all areas of dementia care, but the term wellbeing offers an opportunity for further preciseness of meaning.

In the post- pandemic period, there is an argument that a new emphasis on wellbeing can allow a radical change in the discharge process itself. Post- pandemic there is a requirement for change in how the discharge process is constructed to pull back from the medicalised structure (Degerman, 2020; Goldberg, 2021) that has operated during this period, and been driven by infection control measures instead of person-centred measures. The Appreciative Inquiry process advocates that there are moments when changes in ideology and terminology can be introduced following seismic alterations in events, and the COVID 19 pandemic represents such as occurrence. The introduction of the Health and Care Act (Department of Health and Social Care, 2022c) represents a time of change. The utilisation of this framework may support such a change within the discharge process to enable a new focus on wellbeing. Although existing policy, (National Institute for Health and Care Excellence, 2016) outlined in chapter 3, explicitly requires health and social care professionals to consider the wellbeing of the person living with dementia and their carer, it was clear from the empirical data analysis and systematic review synthesis, that this is often not happening in practice. The requirement for extensive planning and considerations of wellbeing that move beyond the physical (National Institute for Health and Care Excellence, 2016; Social Care Institute for Excellence, 2022) were also identified within existing policy in chapter 3, but the findings of this research project reveal that there is a need for a framework to achieve these ideals in practice.

10.9 Summary

This chapter has compared findings from the systematic review and empirical data. A potential framework to support wellbeing during the discharge process developed from a consideration of the analysis findings across the research project has been outlined. It is acknowledged that it requires further development alongside carers, professionals, and people living with dementia to ensure its applicability and validity. In the next section of this thesis, I will discuss the findings of this research project in relation to established literature and outline the strengths and limitations of the research project, wider implications and further required research.

Chapter 11. Discussion

11.1 What this research project has achieved and the definition of wellbeing within the context of the hospital discharge process.

In this chapter the ways in which the findings of this research project expand what is known about wellbeing for people living with dementia and their carers, during the hospital discharge process, will be presented. I will discuss the key findings of the empirical research project including how the findings align with wider academic literature, how a social constructionist stance enables a nuanced understanding of wellbeing and the value of the Appreciative Inquiry process in identifying changes required to promote wellbeing during the hospital discharge process.

The impact of neoliberalist policies (Mooney, 2012; Schrecker, 2016; Becker, Hartwich and Haslam, 2021) and the impact of COVID 19 on wellbeing during the discharge process will be considered. Implications of the findings of this research project for local NHS trusts, local councils, clinicians, and relevant charitable organisations, such as Alzheimer's UK, will be presented. Towards the end of the chapter the strengths and limitations of the research project will be considered and recommendations for future research made.

At this point I will revisit the aims, objectives, and research questions of the research project. The aim of this research project was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process in both the pre and post COVID 19 contexts. A secondary aim of the research project included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group in the post COVID 19 climate. This included developing a definition of wellbeing within this context using the Appreciative Inquiry approach (Cooperrider and Fry, 2020).

More explicitly, the introductory chapter identified the objectives which included:

1. Conducting a qualitative systematic review to identify and synthesise available evidence regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. *What are the experiences of people living with dementia and their familial carers, during the hospital discharge planning process?*

2. Identifying factors (environmental, organizational, resource or social) that impact the physical, emotional, and social wellbeing of people living with dementia and their carers, during the hospital discharge process, through interviews with health and social care professionals and carers.

3. Exploring if and how the wellbeing and support needs of adults living with dementia, and their carers, are addressed in current hospital discharge practice or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

4. Identifying how guidance from 'COVID 19 hospital discharge requirements' (Department of Health and Social Care, 2020a) impacted on the discharge process during the COVID 19 pandemic.

5. Developing a framework, based on the perspectives of carers and healthcare professionals to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

The research questions of this project included: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

The following sections of the chapter will discuss the findings of the research project. The corresponding objectives were achieved alongside answering the research questions. Objectives 1 and 5 were addressed in the previous chapter and will not be discussed in this section. I will begin by discussing the definition of wellbeing in the discharge context for this patient-carer dyad which addresses the research question: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers?*

11.2 Defining wellbeing within the hospital discharge process.

As discussed in chapter 1, the rising profile of the concept of wellbeing within health care policy, and particularly within policy in relation to the hospital discharge process, requires that wellbeing is defined adequately. Rich qualitative data is required to enable policy makers to understand what wellbeing represents for people living with dementia and their carers during the complex hospital discharge process (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; Department of Health and Social Care, 2020a). This became more important during the COVID 19 pandemic when the Department of Health and Social Care cited the concept of wellbeing in their guidance, within the first six months of the pandemic. It is also appropriate to consult health and social care professionals in their interpretation of wellbeing, as their practice is key to ensuring that policy concerns are achievable in practice for carers and people living with dementia (Harvey and Kitson, 2015).

Wellbeing has been recognised as a socially constructed term (Dodge *et al.*, 2012; La Placa, McNaught and Knight, 2013) and reductive definitions are not useful in this context due to the diversity of meaning for different individuals. This research project has aimed, with the assistance of the Appreciative Inquiry approach, to identify some of the tenets of wellbeing to illuminate the field of wellbeing in this context, in a manner that is meaningful to professional and lay stakeholders. There have been previous attempts to define wellbeing for people living with dementia and their carers (Tyack and Camic, 2017; Stansfeld *et al.*, 2017). Cunningham, Cunningham and Roberston (2018) attempted to identify a definitive definition but were thwarted by the diversity of understandings of wellbeing. Research has attempted to identify extrinsic and intrinsic factors (Stansfeld *et al.*, 2017) for a definitive definition. The definition presented here is specific to the discharge process and is not an attempt to codify a wellbeing definition that can be applied objectively or outside of this context.

The combination of the Applied Thematic Analysis and Appreciative Inquiry methods enabled the incorporation of Kitwood and Bredin's (1992) wellbeing theory into the definition presented here. The importance of defining terms used frequently policy documentation has been discussed widely in numerous sectors to ensure appropriate policy implementation (Iezzoni and Freedman, 2008; Martin and Cobigo, 2011). This definition incorporates the diversity of perspectives from clinicians and carers in cohesion with social constructionist understandings (Berger and Luckmann, 1991). In the introductory chapter, I identified that the UK Government defined wellbeing broadly as including 'physical, social and emotional dimensions of wellbeing' (Department of Health, 2010). The analysis presented in this thesis builds on this broad definition significantly.

Definition: Wellbeing during the discharge process is the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond. Agency is comprised of *processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*.

Identifying and delineating a definition of wellbeing in the discharge context represents an important source of information for clinicians, policy makers and stakeholders. Working with limited information concerning what defines wellbeing or similar terms, impacts upon how policies are devised, actioned in practice, and even understood by stakeholders themselves (Grant, Parry and Guerin, 2013; Rodriguez Santana *et al.*, 2021). It is hoped that the findings of this research project will contribute to greater understanding of how wellbeing can be supported during the discharge process for both carers and people living with dementia. It is understood that working towards a definition is only the first step in this process. Applied research must take place in response to this definition that explores how practical clinician actions, and actionable policies in the acute and community sector, can work towards achieving wider wellbeing. It is also accepted that agency, hope, and personal worth are subjective terms and can be interpreted in different ways by carers and people living with dementia. This chapter will now explore how the findings of the empirical analysis integrate with existing literature in this topic area.

11.3 Discussion of empirical findings and existing literature.

In this section, I will consider how the findings of the empirical study integrate with wider literature regarding the care for people living with dementia, wellbeing, and the hospital discharge process. The discussion of the empirical study findings and their relationship with established academic literature will follow the format of the themes that emerged from the empirical analysis, namely, the content of the themes: Hope, Personal Worth, Agency, and Dream. The factors identified in chapters 5, 6, 7, 8, and 9 in response to objective 2, and in answer to the research question: 'What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?' are discussed within this section in relation to wider literature.

11.3.1 Hope

The theme of Hope revealed that although some health and social care professionals had insight into the experiences and emotions of carers, and people living with dementia, many did not. Therefore, there is a requirement for health and social care professionals to have insight into the requirements of people living with dementia and their carers, that moves beyond considerations of physical wellbeing during the discharge process, to ensure the maintenance of hope. This is not a new finding within the wider literature as caring for people living with dementia and their carers in a manner that considers emotional wellbeing is established both in the academic world, and in the policy documentation considered in chapter 3 (Kitwood, 1997; National Institute for Health and Care Excellence, 2015; Korstjens and Moser, 2018).

The deficiency, identified in the empirical analysis, of emotional support available to carers is unfortunate in the light of the guilt carers described experiencing regarding care home admission. This circumstance has been previously identified as an aspect of the discharge process requiring the provision of further emotional support (Kadushin and Kulys, 1994; Cox, 1996; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). Recent research by Gallego-Alberto *et al.* (2021) has shown that guilt associated with care home admittance remains stable over time. This indicates that there is a need for support in relation to care home discharge destination to be available to carers throughout the discharge process. As early as (2000), Shyu called for a service that supported the mental health and wellbeing of the carers of individuals living with dementia during the discharge process, including in relation to managing emotions and decision making around discharge destination. Other research by Davis *et al.* (2011) has shown that psychosocial support for carers after care home admittance can reduce the burden of guilt for carers over time. The findings of the analysis of the empirical data reveal that there is still a requirement for more robust emotional support for carers, during the discharge process, than is currently available.

The study by Jamieson *et al*. (2015) indicated that support groups for carers online could be a useful source of emotional support during the discharge process which would allow carers to connect with peers and manage their emotions. Further to this, a recent online review has shown that online support groups can be effective in supporting the wellbeing of carers of people living with dementia (Etxeberria, Salaberria and Gorostiaga, 2021). Therefore, it could be argued, based on the findings of this research project, that there is a growing body of evidence detailing the need for more resources to support the emotions present related to the discharge process, with the potential for these to be offered online.

The finding within the theme of Hope that stress, particularly in relation to medication and the day of discharge, had a significant impact on the maintenance of wellbeing is also established within the literature (Cumbler, Carter and Kutner., 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017, Sawan *et al*., 2021). The findings from the study by Coleman and Roman (2015) indicated that carers are often overwhelmed by the medication schedule at the point of discharge, and this was also identifiable within the empirical analysis of this research. Sawan *et al.* (2021) suggested that there should be further integration between hospital and community pharmacists and GPs, with carers directed to a key community pharmacist for advice and support at discharge. Other researchers, such as Walker *et al.* (2009), have supported the introduction of a discharge specialist pharmacist within the hospital and found that this led to fewer medication errors. The findings from this analysis would support an approach that increases access to pharmacists for carers during the discharge process, to avoid the negative experiences of medication on the day of discharge that were evident within the empirical analysis, particularly during the pandemic.

The theme of Hope revealed the importance of ensuring that the needs of people living with dementia are met relating to activities, hobbies, and social outlets. Kable *et al*. (2015) identified that there was often failure to consider social requirements within the confines of the discharge process, and the findings of this study reveal how important it is to consider these less tangible needs of the person living with dementia and their carer. Related to this finding is the need for respite to be considered for carers during the discharge process to enable the continuation of social activities and hobbies that ensure wellbeing. This lack of consideration was a particular issue for both Jack and Amy, who might both have benefited from respite inclusion. Respite has been acknowledged as vital to all carers and particularly those caring for individuals with dementia (Neville *et al.*, 2015). It has been identified in established literature that a significant barrier to respite is both availability and carers not being signposted appropriately to respite facilities (Phillipson, Jones and Magee, 2014; Neville *et al.*, 2015). These studies have not considered the value of respite for the carer being factored within the discharge planning process but only when the person living with dementia is situated within the community. The findings of this study expand upon the importance of respite within the literature to include its value during the discharge process, and not just during periods where the individual is living within the community.

The importance of admiral nurses for the maintenance of hope during the discharge process was outlined by multiple respondents within the data. The admiral nurse is a relatively new introduction into the nursing sector (Bunn *et al*. 2013) but has been identified as increasingly valuable in ensuring the wellbeing of carers in previous literature (Maio, Botsford and Iliffe, 2016). However, an evidence synthesis by Bunn *et al.* (2016) showed that while valued by carers, there is little evidence of the impact of admiral nurses and their role can vary dependent on the needs of the area. There was no evidence available within the systematic review relating to the value of admiral nurse support within the discharge process. This may be because admiral nurses are traditionally based within the community setting and therefore, not integral to the discharge process itself. The findings of this analysis develop the evidence base in relation to what is known about the role of the admiral nurse and the utility of the support they can provide during the hospital discharge process. The role of the admiral nurse should be re-evaluated to consider their worth in relation to the discharge process in the light of these findings. Further integration between community services and acute sector services has been called for within recent policy documentation, and this finding adds further weight to this (Department of Health and Social Care, 2021; NHS England, 2022a).

In the next section, I will consider how the content of the theme Personal Worth intersects with established academic literature.

11.3.2 Personal Worth

An important finding of the empirical analysis was that person-centred care was defined differently by carers, and by health and social care professionals, in relation to the discharge process. Person centred care, often referred to as patient centred care, can have different meanings in different contexts and this has been acknowledged previously within wider literature (Gillespie, Florin and Gillam, 2004). Gillespie, Florin, and Gillam (2004) identified that 'patient centred care' is defined by different professionals in different ways and is dependent on the context and objective of the professional role. Edvardsson (2015) identified that the absence of a shared definition of person-centred care in specific contexts can be problematic. However, this problematic issue has not been discussed previously in the context of the discharge process for people living with dementia and their carers. Therefore, it is an important finding of this study that person centred care must develop a specific definition within this context. The analysis of the empirical data yielded the following potential definition within this context: positive and adequate communication, adequate safeguarding, and an environment free from discrimination. This definition requires further verification, expansion, and development with the aid of people living with dementia as it currently lacks this necessary dimension. Interestingly there is no mention of 'getting to know' the person living with dementia (Kitwood, 1992) and tailoring care accordingly. This may be due to the restrictions of the pandemic context.

Both the systematic review synthesis and findings from the empirical analysis highlighted that poor communication has a detrimental impact on the personal worth and wellbeing of both the person living with dementia and their carer. The empirical analysis also revealed how the language used during the discharge process reflects the inherent power hierarchy of the patient/carer health and social care professional dyad (Goffman, 1961). The empirical data showed that spoken communication for health and social care professionals was often focused on the one-way communication of information from the health and social care team to the carer and patient to ensure clarity. Although often framed as discussions, language choices revealed that the professional participant viewed themselves as the active communicator and the carer or patient as the passive partner. Terms such as ‘allow’ used by health and social care professionals, in relation to patient or carer activities, reveals this power imbalance. Whilst multiple studies have considered how carers and people living with dementia are undermined during the discharge process (Coleman & Roman, 2015) none have specifically explored how the language used is perpetrating this.

The inherent danger of poor communication leading to dangerous or illegal situations was identified within the existing literature (Poole et al., 2014; Boaden, 2016; MacMillan, 2016). The report by Boaden (2016) identified that limited communication, leading to last minute discharges, created potentially dangerous scenarios for people living with dementia. This was reflected in the experiences of the carers who took part in this study and were not given advance warning of their relatives’ discharge date and time. Emmett *et al.* (2014) identified that it was often difficult for carers to safeguard people living with dementia during hospital discharge due to limited communication from health and social care professionals. The repeated absence of appropriate safeguarding for the person living with dementia was identifiable across multiple studies included in the systematic review (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kable *et al.*, 2015; Deeks *et al.*, 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). Kable *et al.* (2015) found that safeguarding of the person living with dementia was often overlooked, particularly in relation to communication connected to medication. The empirical data from this study expands this established finding further as it is not just the person living with dementia who is left unsafeguarded by the lack of communication, but also the carer themselves. This was particularly apparent in the data from both Jack and Amy who were both distressed by the lack of adequate communication which led to an absence of adequate safeguarding.

The role of discrimination within the discharge process was not explicitly addressed during the systematic review synthesis. The role of discrimination in relation to people living with dementia is well established within the literature (Herholz *et al.,* 2002; Milne, 2010). Milne (2010) discusses how being diagnosed with dementia leads to a perception of having lost autonomy and the ability to make decisions, and outlines some of the ways this can be challenged. It was somewhat disturbing to discover that professionals still felt discrimination was playing a significant role within discharge decision making. This finding was not matched within the narratives provided by carers which suggests it may be covert and potentially invisible to carers and people living with dementia. Previous research has pointed to education and role modelling in practice as the key mechanisms to overturn such discrimination (Chan and Chan, 2009). It is important that this analysis has identified the need for the discharge process to be included in training programmes aimed at counteracting discrimination against individuals living with dementia.

The empirical analysis showed that being treated as an expert care partner was vital to ensuring wellbeing for the carer and the person living with dementia. This builds on the findings of previous research which identified this requirement within the discharge process (Bauer et al., 2011a; Mockford *et al*., 2017). Telford (2015) and Bloomer *et al* (2016) found that not being treated as an expert care partner led to an experience of disempowerment for carers and the findings of the empirical analysis develop this further. Both James and Shelly referred to being actively bullied by professionals within the discharge process. No previous study has suggested this level of potential malignancy within the discharge decision making process, and this worrying finding should be further investigated in future research projects to explore whether it is a deviant finding or a more prevalent experience.

Another significant finding of the analysis of the empirical data was the clarity of professional insight into how to treat a carer and/or person living with dementia as a care partner. Professionals identified shared goals, trust and shared decision making as crucial to ensuring that carers and people living with dementia are treated as care partners during the discharge process. Much of the research in this area is focused on areas for improvement within practice or experience primarily (Macmillan, 2016; Mockford *et al.*, 2017). Therefore, this finding is helpful in developing what is known about the professional insight into being a care partner during the discharge process with people living with dementia and their carers. It is also an encouraging finding as it demonstrates that health and social care professionals have a good insight into the actions needed to ensure a positive care partnership and that they were implementing these insights within their practice.

11.3.3 Agency

It was evident from the empirical findings that proactive and supportive professionals are key to ensuring the continuance of agency in the discharge process for people living with dementia and their carers. The value of proactive individual practice is a known phenomenon within dementia care and was evident within the systematic review synthesis. (Cooper and Deeks, 2012; Deeks *et al.*, 2016). For example, Deeks *et al.* (2016) specifically found that individual professional practice was linked to adequate medicine management at discharge. The dementia champions programme has been designed based on an awareness of the value of proactive professionals in influencing quality of care for people living with dementia (Jack-Waugh, Ritchie and MacRae, 2018). The dementia champions programme trains professionals in hospitals to specialise in the care of people living with dementia in their practice area. These programmes are often focused on the ‘care’ aspects of the treatment received by people living with dementia during their hospital stay. This study shows that there is also applicability in relation to the discharge process and ensuring that professionals are cognisant of the positive impact proactive care can have on the wellbeing of individuals who are leaving hospital.

One finding of the empirical analysis was in relation to the prioritisation of physical risk undermining agency. This finding was also evident within the synthesis of the systematic review (Kadushin and Kulys, 1994; Schreiber, Powell and O'Dowd, 2018; Rhynas *et* *al.*, 2018; Hall *et al.*, 2020). Poole *et al.* (2014) found that considerations around risk was often undermining the right of people living with dementia to make their own decisions. Huby *et al.* (2004) found that stringently narrow definitions of risk and risk assessments were being applied broadly and undermining the agency of the person living with dementia and their carer. However, Schreiber, Powell and O'Dowd (2018) identified that this barrier could be overcome if professionals prioritised aspects other than just physical safety. The analysis of the empirical data revealed that both professional participants and carers were in favour of the prioritisation of physical risk being challenged to ensure holistic decision making. This is an encouraging finding as both participant groups agreed on this point suggesting that there is scope to explore this further in future research projects.

Another finding of the empirical data was the detailed professional insight into the processes that ensure agency for people living with dementia and their carers during the discharge process. Professionals used their experience and expertise to identify transparent processes, involving the multidisciplinary team (MDT) and a discharge co-ordinator, alongside formal meetings with carers and the dementia specialist team as crucial to ensuring the agency of people living with dementia and their carers. Jamieson *et al.* (2016) and Gupta *et al.* (2006) identified the importance of the MDT and involving carers in decision making but the specific value of a ward-based discharge co-ordinator and transparent processes were not identified in the systematic review synthesis. Other research has identified the value of the discharge co-ordinator in relation to the discharge process generally (Day, McCarthy and Coffey, 2009) and policy guidance (chapter 3) also recommends the presence of a discharge co-ordinator (National Institute for Health and Care Excellence, 2015). The findings of the empirical study suggest that further research to evaluate the value of a discharge co-ordinator during the hospital discharge of people living with dementia is required.

An area of conflicting narratives between the empirical data of the participant groups was in relation to discharge meetings. Meetings were presented as both vital in supporting agency (Elizabeth) and entirely disempowering (James/Jack). This conflict was also identified within the systematic review synthesis (Cox, 1996; Gupta *et al*., 2006; Emmett *et al*., 2014; Rhynas *et al*., 2018) and suggests that there is a requirement for further research into the value of the discharge meeting itself and the factors that enable it to aid people living with dementia and their carers to maintain agency. Discharge meetings have been acknowledged to function differently in different contexts (Waring, Marshall and Bishop, 2014) and further codification of the steps required to ensure a successful and empowering discharge meeting is warranted.

In this section I have reflected on how the findings of the empirical research intersect with wider academic literature in this area. Divergences with established literature were outlined and the contribution of new evidence from this research has been identified. In the next section, I will consider how the findings of the research project align with a wider critical discussion of the inequality of people living with dementia and their carers.

11.4 Alignment of the research project findings with the wider critical discussion regarding the wellbeing of people living with dementia and their carers.

Objective 3: To explore how the wellbeing and support needs of adults living with dementia and their carers are addressed in current hospital discharge practice or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

Objective 3 aimed to evaluate how wellbeing is addressed within the discharge process and whether wellbeing requirements are currently overlooked and if so, why. The answers to these questions are complex and driven by numerous organisational, structural, and personal factors explored in the findings of the empirical study, including individual professional practice, the absence of transparent discharge policy and the pressure exerted on inpatient and community services. The findings of this research project reveal that the medical model of illness and medical hierarchy within the institution of the hospital, are still the dominant forces within the discharge process for people living with dementia and their carers (Goffman, 1961; Engel, 1977). The empirical data analysis and the systematic review synthesis showed that carers and professionals felt that the discharge process was often being driven by financial considerations, pressures on bed availability and clinical staff availability. It is also evident that the strength of these constructed paradigms was exacerbated by the COVID 19 pandemic and its regulations.

Considerations of risk and decision making driven predominantly by health and social care professional interests, appear consistently in the empirical data across both participant groups. Although policy is clear that the wellbeing of people living with dementia and their carers should be central to the discharge process (National Institute for Health and Care Excellence, 2015), it is evident from the findings of this research project that this is often not happening in practice. This finding was not unexpected, as previous research has pointed to this conclusion (Mockford, 2015; Mockford *et al.*, 2017). This finding also aligns with wider academic critical gerontological discussions in relation to older people within society and particularly, older people living with dementia and the discrimination and stigma they face (Townsend, 1981; Holstein and Minkler, 2007; Van Dyk, 2014). A version of this narrative has played out across the pandemic. Older people have been objectified as ‘vulnerable’ and positioned as largely to blame for social distancing restrictions needed to protect them in their ‘vulnerable’ status. Other academics have explored this representation and critiqued how it has been exploited throughout the pandemic (Lichtenstein, 2021; Silva *et al.*, 2021). Silva *et al.* (2021) identified how ageist assumptions and prejudices manifested in relation to resource allocation during the pandemic. The same prejudices were discussed explicitly within the data regarding the reluctance to refer people living with dementia for rehabilitation during discharge due to the assumption that they would not be suitable.

In chapter 3 it was identified that the policy available before the onset of the pandemic (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016) required that professionals must consider the wellbeing of people living with dementia and their carers during the hospital discharge process. The findings from the analysis of the empirical data identify that wellbeing is overlooked during this process. The policy discussed (National Institute for Health and Care Excellence, 2015) also required that hospital discharge should be a well-planned process which places patient and carer needs above internal pressures. The fulfilment of this requirement was sometimes evident within the analysis of the empirical data but carers frequently reported experiencing no discharge planning at all. In chapter 3, I stated that following the analysis of data from the empirical study I would identify whether the 2016 quality standards (National Institute for Health and Care Excellence, 2016) are being upheld in practice. The analysis would suggest that the standards are not being upheld. However, the pandemic setting of this research project may not be representative of standard practice and therefore, there is scope for further research in this area to clarify this further.

11.5 Comparison of findings with other recent research in this area

A recent study (Reeves *et al*, 2023), using data from the Hospital Episodes Statistics datasets for England 2010/11, 2012/13 and 2016/17 and analysing over 5 million hospital discharges identified that people living with dementia have a 30% increased risk of death within thirty days of discharge, in comparison to people living without dementia. The authors suggest that this may be linked to an inability to recognise when a person living with dementia requires palliative support, rather than acute treatment. Alternatively, there is a suggestion that it may be linked to people living with dementia being discharged inappropriately, or without the correct community support in place.

Further to this, the authors identified that although many initiatives to improve the experience of people living with dementia during their hospital stay were implemented during this period, no improvement in outcomes was identified. The authors consider whether this may be because outcomes are influenced less by hospital culture, and more by service availability, for example, staff shortages, limited community social care resources and the pressure to free up beds.

This conceptualisation was reflected in the findings of this thesis. Staff shortages during the COVID 19 pandemic and significantly curtailed social care service availability in the community, were identified as impacting negatively on the discharge process by health and social care professionals. The pressure to ‘free up beds’ was also identified by carer participants and health and social care professionals, who lamented the impact of this pressure on their ability to plan the discharge process effectively and in a person-centred way. The data used in the Reeves *et al* (2023) analysis did not include pandemic data and therefore, does not reflect the period and experiences of the participants of this study.

However, the findings of this study argue that by adopting a focus on wellbeing and what can support wellbeing in the hospital environment, there may be a way to improve patient experience. This was a perspective supported by participants and professional interviewees. The social constructionist approach suggests the value of changing hospital culture to being wellbeing focused, in contrast to linking poor outcomes to service and staff availability only. It could be argued that if there is an absence of focus on wellbeing and supporting wellbeing, even with greater staff availability and service provision, nothing will change or improve. The authors (Reeves *et al*, 2023) also identify that data regarding patient experiences, including of the discharge process, was not captured in the Hospital Episodes Statistics datasets. Therefore, the findings of this study reveal the perspectives of carers regarding the discharge process and add to what is known qualitatively about this process.

11.6 Social constructionist understanding of the discharge process.

The discharge process should place the needs of people living with dementia and their carers at its heart according to available policy guidance (National Institute for Health and Care Excellence, 2015). The experiences discussed by participants within this research project suggest that health and social care professionals are often placing the concerns of the hospital and social services system centrally instead. This is evident from professional participant focus on the risk of falls predominantly and the pressure to discharge quickly, particularly within the COVID 19 guidance (Department of Health and Social Care, 2020a). Within this guidance (Department of Health and Social Care, 2020a) there was a pressure to discharge quickly, even when the action was inappropriate for the carer and person living with dementia. This finding relates to wider concepts regarding the inequality people with dementia and their carers experience (Herrmann *et al.*, 2018). Further to this, one could argue that the position of this carer-patient dyad is being socially constructed within the discharge process as a reflection of their wider position within society (Townsend, 1981; Swaffer, 2014; Eisenberg, 2009). This aligns with the theoretical concepts outlined by Foucault (1973) in relation to the power structures created by institutions, which ultimately position patients below the needs of the institution itself. Furthermore, it supports the tenets of theorists who suggest that language is used to support hierarchies, through terms such as risk, which ultimately underpin the dominant concerns of the institution (Derrida, 1970).

The theoretical concept that risk is utilised as a mechanism to support the concerns of the institution above the needs of the individual, corresponds with the findings of the synthesis of the systematic review. Norman (2003) and Rhynas *et al.* (2018) both found that the opinions of health and social care professionals, regarding concepts of risk, were elevated above the opinions of carers and people living with dementia. This ultimately undermined the patient/carer dyad influence on the discharge process.

This finding was mirrored within empirical data where bureaucracy was also a barrier undermining the influence of people living with dementia and their carers. This suggests that people with dementia and their carers are not valued within the discharge process to the same degree as the value placed on the system itself. This would complement Berger and Luckmann’s (1991) concept of shared common worlds which thrive through externalisation, objectification and subsequent internalisation, for example, of concepts of risk that ultimately disempower people living with dementia and their carers while supporting the needs of the hierarchy. This imbalance between the value of the process and the value of the patient/carer dyad needs to be addressed urgently if policy which supports the prioritisation of wellbeing is to be upheld in hospital discharge practice (National Institute for Health and Care Excellence, 2015).

A social constructionist approach would suggest that there are several ways this can be achieved (Camargo-Borges and Rasera, 2013). The process of leaving the hospital is constructed between the actions and dialogue of carers, health and social care professionals and people living with dementia themselves (Harding and Palfrey, 1997). Therefore, changing the discharge process involves re-thinking and re-imagining the procedure to centralise wellbeing for people living with dementia and their carers. This is an approach supported by the empirical data, as both carers and professionals were in favour of further focus on the wellbeing of people living with dementia and their carers, than is currently present within the discharge process.

One potential solution is for assessments and decisions to be re-constructed to focus primarily on wellbeing with the carer and person living with dementia being positioned at the centre. This was something carers requested in the empirical data. Face- to- face meetings immediately after admission, where carer and patient opinions are regarded as of equal, or even more importance, than medical concerns would change the landscape of this process. Good examples of this were revealed by the experience of Elizabeth who felt her needs and concerns were prioritised by health and social care professionals. It is important to learn from the negative experiences of carers such as James and Shelly. A change in language usage to move away from words such as risk and safety and towards words such as enablement and empowerment would be required to support this change in how the process is understood and co-ordinated. The professional participants of the empirical study suggested that these changes would be feasible and supported in practice. Furthermore, these changes would be supported by the tenets of Foucault (1973) and Derrida (1970) and enable the character of the discharge process to change significantly. This would represent a substantial change, not necessarily in the discharge process as it stands, but in its emphasis. All these potential alterations are supported by the findings of the analysis of the empirical data of this research project and underpinned by the systematic review synthesis findings.

A change of this magnitude would need to be implemented in many ways as indicated in guidance to facilitate change issued by NHS England (2013). A shift in policy towards centralising wellbeing instead of merely addressing it (National Institute for Health and Care Excellence, 2016) would represent a step forward. The development of a framework to ensure wellbeing during the hospital discharge planning process for this patient/carer dyad represents a first step to achieving this change in emphasis. The framework developed within this research project is a natural conclusion to the findings identified through the Appreciative Inquiry approach of the empirical project and the systematic review synthesis. This section has considered how the findings of this research project echo the wider academic discourse regarding the positionality of people with dementia and their carers within society. It has also considered how a social constructionist understanding of the discharge process could lead to a change in focus towards wellbeing. In the next section, I shall consider the findings of the Dream section of the empirical data analysis and how the findings relate to wider academic literature.

11.7 Discussion of Dream section findings

In this section, I will discuss how the findings of the Dream segment of the analysis intersect with wider academic literature. During interviews both professionals and carers were asked to Dream (Cooperrider and Whitney, 2005) about improvements they believed would benefit the discharge process. This is an important aspect of the Appreciative Inquiry process as the expert knowledge of participants regarding the strengths and weaknesses of a process is identified. Carers requested more information and support during the discharge process regarding the financial implications of their decision making. The significant financial impact of a dementia diagnosis (Alzheimer's Society, 2023) and the increasing carer financial burden has been discussed in recent literature (Bayly *et al.*, 2021). The findings of the empirical analysis suggest that further information regarding the potential costs of different discharge options should be available during the discharge process for the carer.

Further signposting was requested by carer participants. The importance of adequate signposting and the impact of not receiving appropriate signposting has been identified previously, although not in this context (Hagan, 2020). The need for further signposting may indicate a role for the dementia care navigator within the discharge process (Bernstein *et al.*, 2019). Dementia care navigators are currently a community support service with a limited evidence base (Bernstein *et al.*, 2020). Further integration between hospital services and the community-based care navigator service may offer the possibility of providing the signposting services requested by carers. Further integration may also address issues identified in relation to transport if care navigators are able to signpost potential options.

The request of health and social care professional participants to re-introduce ward based social workers echoes a recent letter (January 2023) from the Adult Principal Social Worker Network to the Secretary of State for Health and Social Care and the Minister of State for Social Care, which argued for the re-introduction of ward based social workers (Adult Principal Social Worker Network, 2023). Recent evidence has considered the role of ward based social workers and identified that there is a research gap in relation to the contribution and value of the social worker role in this environment (Heenan and Birrell, 2018). Further evidence is required that considers how the social worker role could support the wellbeing of people living with dementia and their carers during the hospital discharge. This role could potentially address many of the issues identified by carers in this analysis, including limited communication and signposting.

There was mixed evidence regarding the request by both carers and professionals to assess discharge options in the community (NHS Providers Community Network, 2022; Jeffery *et al.*, 2023). The discharge to assess model implemented during the pandemic was praised by participants but the potential for inappropriate discharges was also highlighted. Some academics have recently identified that the benefits of the discharge to assess model are not fully known (Jeffery *et al.*, 2023). The NHS Providers Community Network (2022) has argued that discharge to assess models are cost saving and enable hospitals to manage workloads more effectively. Ultimately, discharge to assess models are based on funding availability and extra research into the impact of this model on the wellbeing for people living with dementia and their carers is needed.

The next section of this chapter shall further consider the socio-political context of the discharge process and additional reasons why the focus of the process should be on supporting the wellbeing of people living with dementia and their carers.

11.8 The socio-political context of the discharge process and the requirement for a different approach.

Previous discussion within this chapter has revealed the requirement for a different approach to healthcare policy in relation to people living with dementia and their carers. It is arguable that a different approach could be achieved through a change in the political theory within the health and social care sector in the UK. The marketisation introduced into the NHS via the Health and Social Care Act (2012) was heavily criticised for its emphasis on competition rather than collaboration (The Kings Fund, 2012). The ongoing focus of austerity over the previous ten years has led to cuts in public services, local governments and NHS funded bodies which have striven to find ways of reducing their budgets (Stuckler *et al.*, 2017). Stuckler *et al.* (2017) has argued that austerity measures have had a significant negative impact on the most vulnerable in society in relation to health care accessibility. An issue that arose frequently in interviews was the complexity of the system for carers and the lack of clarity around funding options and finance, and how this prevented any emphasis on wellbeing within the process. Michael, Jack, Anne, Shelly, Elizabeth, and James all discussed at length the problems this caused for the people they cared for, and the cumulative impact on their own wellbeing.

A variety of the participants discussed the inaccessibility of support for carers and the patchiness of provision in care packages and admiral nurse availability. Some academics (McGregor, 2001; Schrecker, 2016) would argue that this is the outcome of pervasive neoliberal policies within the health care system (Becker, Hartwich and Haslam, 2021). Neoliberalism (Sakellariou and Rotarou, 2017) is largely defined as a political epistemology which emphasises the free market above the rights of individuals to health and social care. The impact of the neoliberal agenda has demanded de-centralisation of services and the invasion of market forces causing risk and responsibility to be laid on the individual (Mooney, 2012; Collins, McCartney and Garnham, 2016). Globally, this has led to inequities in access to healthcare and criticism that the most vulnerable are often severely disadvantaged (Sakellariou and Rotarou, 2017; Baru and Mohan, 2018) These themes were reflected in the data with carers feeling abandoned to manage risk around medication (Harriet) or struggling to organise and pay for equipment (Amy).

The data from this study supports the perspective that there is a pervasive neoliberal influence within the hospital discharge process. Carers often spoke about paying out of their own pocket for support or decrying the bureaucracy of systems that at the end of a long process, do not allow access to any financial support. This was experienced by both Jack and Anne. Academics have argued that the marketisation of healthcare is corrosive and ultimately devalues the worth of non-financial aspects of the discharge process, for example wellbeing, whilst simultaneously valuing the cost of services and treatments (Feiler, Hordern and Papanikitas, 2018). Therefore, it can be argued that the neoliberal agenda identified in the discharge process is having a negative impact on the wellbeing of individuals with dementia and their carers.

This argument is supported by wider academic research which has identified that the neo-liberal focus on the responsibility of the individual leads to high rates of anxiety and the internalisation of negative psychology (Sugarman, 2015). It is worth at this point identifying that a neo-liberal approach would not support the notion of wellbeing as a sound objective of the hospital discharge process. It would expect both the market and individuals to provide this independently. Neoliberal perspectives would not identify any responsibility on the part of the health and social care system, or the UK government, or collectivism towards supporting wellbeing (Pownall, 2013). If the experiences described by professionals and carers of limited community service availability, and a lack of clarity in relation to the discharge process are due to de-centralisation because of a neo-liberalist agenda, this must be addressed by a shift in policy away from marketized health and social care. Many academics and professionals have argued for this previously as the result of a neo- liberal health and social care system for people living with dementia and their carers is bleak (Mooney, 2012). The over emphasis on individualism can exert a terrible toll on carers and people living with dementia within the community and this is also true of the hospital discharge system (Ramon, 2008).

However, the UK still has a universal health care service and social care system (even if means tested) and it has been identified that there is the ability to improve on current practice and make choices that move away from de-centralisation and assigning responsibility to the individual and their carer (Adams *et al.*, 2019). There have been policy decisions made during the pandemic which move away from neo-liberal approaches. The introduction of furlough and the public health campaign which urged people to think as one integrated society, ‘thank you NHS,’ rather than acting in self-interest. This, alongside the decision to prioritise the needs of those classed as ‘vulnerable,’ reveals that the UK general population still have some ideals that would support the centralisation of wellbeing within the discharge process. It has also been shown that populations balk at the concept of neoliberal societies and prefer concepts of fairness and justice. This ensures that political policies, such as austerity measures, are not popular (Kashima, 2019).

Within the new Health and Care Act (Department of Health and Social Care, 2022a), there has been a marked shift away from de-centralisation and emphasis on market competition and towards collaboration via Integrated Care Boards. However, criticism from The Kings Fund (The King's Fund, 2021) has highlighted that the Act has significant limits and does not address the financial difficulties of the health and social care system, nor does it delineate how collaborative approaches between different bodies shall operate. The results of this study would indicate that a tonal shift towards wellbeing is required to re-focus policy to ensure that health and social care is focused on the needs of the individual and not the system. A movement away from neoliberal emphasis on competition in favour of collaborative approaches, would support a shift towards wellbeing being a central concern of the discharge process. In this section, I have considered how the recent change in the socio-political landscape away from neoliberal concerns may enable wellbeing to become centralised within the discharge process. In the next section, I will consider how COVID 19 impacted on the discharge process further and what lessons may be abstracted to aid any future pandemics.

11.9 The impact of COVID 19 and lessons to be learnt.

Objective 4: Identifying how guidance from ‘COVID 19 hospital discharge requirements’ impacted on the discharge process during the COVID 19 pandemic.

COVID 19 had a significant and penetrating influence on the discharge process. The ways in which COVID 19 affected the discharge process are presented within the findings chapters of this thesis. There is a requirement to learn from the pandemic and the conditions it created to improve the discharge process. The two most significant ways in which the discharge process was impacted by the

COVID 19 pandemic was evidence of a faster discharge process and the curtailing of visiting. These impacts shall now be discussed.

In chapter 3, I discussed the policy introduced during the pandemic in relation to the hospital discharge process at length. In this section, I will revisit the policy to identify how the empirical findings are related to the policy issued. The original guidance issued in section 1.3 of the COVID-19 Hospital Discharge Service Requirements (Department of Health and Social Care, 2020a) in March 2020 placed accountability on acute hospitals to discharge all patients home where possible. The discharge to assess model was introduced (section 1.8) which aimed to promote assessments being completed in the community following hospital discharge. The discharge lounge was established (section 2.2), which quickly moved patients away from the wards on which they had been cared for into transitionary wards once the decision to discharge was made. Clarity was delivered in relation to funding being available (section 2.8) to enable quicker discharges where social care was required. Therefore, priority was given to discharging people living with dementia as quickly as possible above all other concerns and considerations. The result of this was identified by carers and health and social care professionals within the empirical analysis of this study, namely, the creation of a discharge process that was occurring too quickly, with the correct assessments not being carried out.

The letter addressed to all Trusts on 17 March 2020 urged that alongside social distancing measures, visits to patients were to be curtailed with phone calls offered as a potential replacement. It is known that most hospital NHS Trusts stopped visiting or reduced visiting significantly during this period and the impact of this was discussed by carers at length within the data. The impact of an inability to visit was identified by a number of carers as having an extremely negative impact on the discharge process. Any agency or sense of control over actions for carers and people living with dementia was prevented due to the policy introduced during the pandemic.

A recent systematic review by Bailey *et al.* (2022) identified 14 papers outlining the experiences of informal carers during the pandemic period. Fear and uncertainty were identified as two of the themes across the published research. This direct correlation with the findings of this study reveals the importance of this analysis for presenting the impact of the pandemic in this context and for this carer dyad. The research published considering the wellbeing of people living with dementia and their carers during the pandemic by Hanna *et al.* (2022) and other academics (Lightfoot *et al.*, 2021; Maćkowiak *et al.*, 2021), has been community focused and identified problems for carers, such as loneliness and isolation in the community, and the inability to access community services (Sriram, Jenkinson and Peters, 2021). The findings presented in this thesis outline how these experiences in the community were echoed within the hospital discharge process. The available evidence from the review (Bailey *et al.*, 2022) does not include professional perspectives of the pandemic alongside carer narratives. This further highlights the unique nature of the analysis available in this research project and addresses the secondary aim to expand the evidence base available to clinicians and policy makers in this topic area.

A crucial lesson to be learnt from the impact of the COVID 19 pandemic guidance was the negative impact of the prioritisation of medical concerns above social concerns for patient wellbeing. Carer narratives revealed how distressing this was for the carer and person living with dementia, and how difficult it made arranging an adequate discharge. This experience was outlined by Jane, Katie, Jack, and Carol who all faced significant difficulties due to pandemic guidance and policy. The policy approach taken should not be repeated in future pandemics for people living with dementia. It is the contention of this thesis that relegating wellbeing and person-centred care as a secondary concern to infection control measures, is not appropriate for people living with dementia and their carers, within the hospital discharge process. The inappropriateness of the Government guidance during the pandemic for people living with dementia has been identified in Talbot and Briggs (2021), who advocated for more nuanced and accessible guidance. The findings of this research would support this nuanced approach in future pandemic contexts.

As previously mentioned in chapter 3, the Judgement delivered by the high court on April 27th, 2022, found the policy issued between 17th March and April 4th, 2020, unlawful, and guilty of failing vulnerable adults being discharged from hospital (Holt, 2022). This judgement vindicated the argument of this thesis, and its contention that future policy should focus specifically on ensuring the wellbeing of people living with dementia and their carers above other concerns including infection control. Emerging evidence supports this conclusion (Hughes, Liu and Baumbach, 2021; Wong *et al.*, 2022; Hanna *et al.*, 2022) with research showing that the emphasis on infection control measures outside of the hospital discharge process, led to negative outcomes for people living with dementia and their carers. However, some research has suggested that infection control measures may not always be a barrier to the wellbeing of adults living with dementia in the hospital context, if there is an awareness of the need for a balanced approach (Page, Davies-Abbott and Jones, 2021). Page, Davies-Abbott and Jones (2021) used the dementia care mapping method to identify that wellbeing on acute wards could still be high for people living with dementia, even during the pandemic with prolific use of PPE, if mental health nurses acted to modify the impact of pandemic regulations. This demonstrates that there is a requirement for significant flexibility in the infection control measures applied to people living with dementia and their carers that can prioritise wellbeing where necessary.

This section has demonstrated the importance of not relegating the wellbeing of individuals to secondary importance in pandemic contexts. In the final section of this chapter, I will reflect on the limitations of this research project, the further research required to advance the evidence base in this field and the implications of the research for policy makers, health and social care providers, integrated care boards, clinicians, and charitable bodies. Lastly, we will reflect on the importance of maintaining wellbeing for people living with dementia and their carers and the value of this research project.

11.10 The value of the Appreciative Inquiry process and the importance of the concept of wellbeing within the discharge process

The Appreciative Inquiry process (see chapter 4 for summary of the approach) was invaluable in revealing the insights and ideas of professionals and carers, in relation to wellbeing within the hospital discharge context (Whitney and Trosten-Bloom, 2010), and the factors that ensure wellbeing for this carer dyad. Engaging in the Appreciative Inquiry cycle (Cooperrider and Whitney, 2005) allowed the perspectives of carers and health and social care professionals to be central to these first stages of the potential change process, in accordance with social constructionist concepts of constructed entities (Cooperrider and Whitney, 2005).

Definition, discovery, dream, design, and destiny were incorporated into the method of the research project which aimed to ‘define’ wellbeing for carers and health and social care professionals, ‘discover’ the perspectives and experiences of this population of the hospital discharge process and ask them to ‘dream’ of improvements to the overall process (Bushe, 2011). The ‘design’ of the wellbeing framework was also facilitated. The final ‘delivery aspect’ of the Appreciative Inquiry cycle was not part of this research project. Understanding the insights of professionals into what they believe would improve the discharge process is vital to ensuring that any future implementation study, which would complete the ‘delivery’ aspect of the cycle, is feasible and would be supported by professionals.

The Appreciative Inquiry method allowed explicit consideration of the perspectives of health and social care professionals and carers, of the changes that would enable the discharge process to focus on wellbeing. In accordance with the Appreciative Inquiry method (Cooperrider and Whitney, 2005), the focus on evident strengths of the discharge process allowed this research project to focus on how wellbeing is, and could be, further supported in practice. This is in opposition to a problem-solving based approach which focuses on weaknesses within a process. Analysis of the ‘dream’ section of the carer data revealed that a move towards wellbeing would also be welcomed by this patient-carer group. Carers requested further respite, signposting, information about financial implications and explanation, and support to enable them to navigate the discharge process and this was discussed within the findings chapters.

The Appreciative Inquiry process used within this project was similar to the process outlined by Scerri, Innes and Scerri (2019). I asked participants to describe their positive experiences, and I highlighted these experiences in the findings section and to inform the framework. Scerri, Innes and Scerri (2019) developed ideal scenarios in workshops, I asked participants to detail what may have improved their experiences, and the outcomes of these discussions are detailed in the Dream section of the findings. Carers often had insight into the actions that would have improved the process and were detailed in their need for explanation, respite, being given choices, clarity regarding medication management and more specialist dementia nurses.

Michaels (2005) and Havens, Wood, and Leeman (2006) and Carter *et al* (2007), identified that focusing on successes can help further achievements, and help move towards positive improvements in a process. Further to this, Carter *et al* (2007) argued that the Discovery and Dream phases should take place simultaneously. This occurred within my research project across both interview sets, and I ensured the follow up of any positive stories within interviews. Professionals were asked to reflect on the best aspects of the process, alongside considering what could improve the process. Reed *et al* (2002) identified the importance of listening to both positive and negative stories, and similar to the work of Page (2020), this was facilitated during this project by asking generative questions (Gergen, 1982) from the topic guide such as- what support (emotional/physical/social/practical) did you receive during the discharge process from health and social care professionals? What went well during the discharge process? What support has helped you to maintain your physical and emotional well-being following your relative/friend’s hospital discharge?

Hammond (1998), Havens, Wood, and Leeman (2006) and Reed (2007) identify that it is important within the Appreciative Inquiry method to include all findings, and not gloss over negative findings, or ignore some findings in favour of more positive narratives. I also adhered to this tenet and included negative findings within both the findings chapter and in the framework. It is important to learn from both positive and negative narratives and Reed (2007) identifies that the flexibility of the Appreciative Inquiry method is one of its strengths in relation to form and function. I also found this, as the Appreciative Inquiry approach allowed me to utilise interviews to identify potential strengths of the discharge process, but also areas that require improvement without having to ascribe to a particular method. Further to this, different Appreciative Inquiry projects utilise different methods of development and progression of their findings and outcomes. While I developed a framework, other researchers as described in Trajkovski *et al* (2013) and Page (2020), have progressed their findings through workshops, focus groups or returned to an earlier phase of the Appreciative Inquiry cycle. Reed

(2007) identifies that the Appreciative Inquiry process is not linear and re-visiting earlier research phases can be a part of the research process. This flexibility entails that developing the findings from this project in future research can be adapted as required.

Carter (2006) identified that it is important that any Dream concepts are representative and achievable, and this can cause some problems within the Appreciative Inquiry method if participants have unrealistic expectations. However, I did not find this to be problematic with either group of participants who had lived experience of the processes of discharge, and reasonable insights into changes needed. This finding was also reflected in the work of Page (2020) who identified that the Appreciative Inquiry method can help professionals to glimpse potential changes to practice. Professionals often identified changes in paperwork or interprofessional working, which would be achievable. Similar to the findings of this project, Hammond (1998) identified that language usage is central to changing processes, and I also came to that conclusion within this project, particularly in relation to the term wellbeing.

Scerri, Innes and Scerri (2019) and Reed (2007) identified that Appreciative Inquiry has a potential strength in its specificity and context explicit focus. This was helpful during this project due to the impact of the pandemic and the way it impacted upon the discharge processes. The context specific nature of the Appreciative Inquiry process has allowed for the development of the framework and will allow specific focus on this context for this carer- patient dyad. Scerri, Innes and Scerri (2019) and Trajkovski et al (2013), identified the importance of key stakeholder buy- in within the cyclical process of the Appreciative Inquiry method. Shendell-Falik, Feinson and Mohr (2007) and Page (2020), utilised workshops and focus groups to develop the findings of their Appreciative Inquiry further. For this project, the development of the framework would benefit from following the methods of these previous projects and utilising workshops with stakeholder input. Page (2020) identified that the Appreciative Inquiry four phase process allowed the nurses in his study to change their understanding and attitudes towards people living with dementia. Although in my study participants were only interviewed once, it was evident that the reflection occurring during the conversations was allowing participants to move towards an understanding of the importance of tolerating some risk to support individual wellbeing.

The importance of higher level and management stakeholder input was identified by Turner *et al* (2017) and would be an important consideration for progressing the framework in future research outside of the scope of this thesis. Further to this, Carter, Cummings and Cooper (2007) identified the importance of developing timelines and achievable plans for implementing change. This would represent a valuable future project for the development of the findings of this project.

This section has considered the strengths and weaknesses of this research project. The Appreciative Inquiry approach has been identified as a significant strength, alongside the inclusion of both carer and professional insights. In the next section, I will identify the further research required in this area which has been revealed by this project’s findings, including the development of the wellbeing framework, research in conjunction with people living with dementia and the need for an ethnographic study.

Chapter 12. Conclusions of project

The primary aim of this research project was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. A secondary aim of the research project included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group in the post COVID 19 climate.

The Appreciative Inquiry method has shown the need for change within the process, and specifically the requirement for wellbeing to be centralised within future hospital discharge practice. The framework developed from the findings of the project indicates that there is a requirement for the wellbeing needs of people living with dementia and their carers to be placed at the heart of the hospital discharge process.

The six areas of the framework outline the main areas which require change and further consideration within the discharge process. These are: for wellbeing to be a primary concern of the discharge process that moves beyond only physical pre-occupations; for there to be a tolerance of risk within discharge planning; the need for a clear road map available of the discharge process for the carer (transparent processes); for the carer and person living with dementia to be care partners with health and social care professionals; a need for the identification of adequate resources for carers and people living with dementia (accountability); and for the centralisation of the carer and person living with dementia, within the process, from admission to discharge.

Professionals within the discharge process must ensure that individuals living with dementia, and their carers, are able to maintain hope, personal worth and agency. This holistic approach can be achieved through a reconsideration of the process to prevent the dominance of the hospital concerns and preoccupations during hospital discharge.

In response to the primary aim of this research project, the facets of wellbeing during the discharge process include the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond. Agency is comprised of processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking. Hope is defined by moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers). Personal worth is comprised of ensuring person-centred care and being treated as a care partner. These concepts have been developed in both the findings and discussion chapters of this thesis.

A secondary aim of the project was to further develop the evidence base available to policy makers, clinicians, and academics in this area. The impact of the pandemic, and pandemic policy, on the discharge process has also been outlined, and the requirement to balance infection control measures with wellbeing for this demographic in future comparable scenarios has been identified. Further definition of the concept of wellbeing and potential changes to the process have been outlined, contributing to the requirement to develop the evidence available further.

12.1 Limitations and strengths of the research project

As with any research project, there are several limitations that should be considered when interpreting the evidence presented. One of the earliest findings of the systematic review synthesis was that carers often undermine the viewpoint of the person living with dementia. Due to ethical constraints and the impact of social distancing due to the pandemic, I could not directly speak to individuals living with dementia about their wellbeing or the hospital discharge process. I believe that the opinion and perspective of people living with dementia should be sought on all topics and that further research is required to address this gap in the evidence available. Future work should look to focus on the perspectives, opinions, feeling and thoughts of people living with dementia singularly. There is a need for future ethnographic work in the hospital context with people living with dementia to understand their perspective of their own wellbeing and how that could be increased. Such a project would be feasible in the post- pandemic context where access to hospital spaces is no longer restricted.

The Health Foundation (2021) reported on some of the challenges faced by the NHS and the social care sector due to the pandemic. Staff shortages were caused by isolation requirements, health and social care professionals being ill with early variants of COVID 19, parents' inability to work due to schools being closed or other caring duties. It was challenging in this context to recruit many of the professional groups' integral to the discharge process.

The limited number of professionals interviewed for this research project reflects the lived reality that services were extremely stretched by the pandemic context. On one occasion, a physio therapist cancelled an interview three times due to the workload caused by colleague absences. The limited data collected is a limitation of this research project, however, due to the unique period in which this study was undertaken, and the unique data collected during this specific period, it is important to recognise the value of the data collected during these very pressured times.

It was also challenging to recruit spousal carers during the pandemic context due to the immense pressures that carers were under during this time. There was no respite available, no day centres and no legal way to mix with other families during the pandemic. Therefore, many interviews took place with carers and the person living with dementia present. Carers could not leave the person living with dementia and therefore, interviews were often interrupted by carers needing to attend to the needs of the person living with dementia.

I was unable to access any physical locations during this research project due to the impact of the pandemic. I was unable to implement an ethnographic study which I still believe is required to address the research gap in relation to wellbeing during this process. These restrictions caused by the pandemic context reflect another identified limitation. Interviews were carried out during England's lockdown in 2021 before the presence of a vaccine in any significant capacity, and later in the year as the country began to unlock in Summer 2021. Therefore, the interviews reflect the manner of the hospital discharge process during this period. It could be seen as a limitation that the data reflects this unique period. However, this limitation is in many ways a strength of the research project. The experiences of carers and health and social care professionals during the pandemic is captured in the data and is therefore, valuable in highlighting the perspectives and opinions of individuals during the COVID 19 pandemic.

This research project was a qualitative project carried out remotely during the pandemic. As a result, its wider applicability is limited outside of theoretical development. However, the aim to develop the evidence base in this area and the concept of wellbeing for people with dementia and their carers within the context of the hospital discharge process, is a worthy and valid endeavor. Due to the subjective and socially constructed nature of the concept of wellbeing, it is necessary that rich qualitative data is accessed that fleshes out this concept further. Due to the rising profile of the concept of wellbeing within health and social care policy and particularly in relation to the discharge process, further development of this concept and what it means to carers and professionals is essential. Identifying the factors that carers and professionals believe ensure wellbeing during this process is also important for advancing professional practice, policy, and indicating where further research is required.

Another limitation of the research project is the constraint to the consideration of wellbeing within the hospital discharge process only. As this undertaking represents a qualitative project focusing on the hospital discharge process during the COVID 19 pandemic, there is no capacity to focus broadly on the social care sector or domiciliary care in the community. These topics are valid research areas which require further exploration and consideration. There is an argument that wellbeing within the discharge process is simply part of a wider conversation about how carers and people living with dementia are treated. However, that discussion is for future and larger research projects to explore.

There were several strengths to this research project. One strength is the ability to access both carer and professional perspectives on this topic. Previous research has often focused on carer or professional perspectives without combining and comparing the data (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016). This research project has benefitted from being able to compare both perspectives to enable a more nuanced analysis of wellbeing in this context. The Appreciative Inquiry (Cooperrider and Fry, 2020) analysis enabled a focus on positive areas of the discharge process allowing the revelation of actions that support wellbeing. The Dream aspect of the Appreciative Inquiry method enabled a focus on the changes professionals and carers would advocate for within the discharge process, and this has enabled the beginnings of the development of a framework to include wellbeing as a central consideration during the discharge process.

12.2 Further research required.

Firstly, the framework included in this section requires significant further input from professionals and carers and people living with dementia. It requires development and refinement within the NHS setting. Its usage requires analysis by professionals and piloting of the framework in the post- pandemic period to fulfil the ‘design’ phase of the Appreciative Inquiry cycle. The specific actions required during the discharge process to implement the framework need further investigation in context. Such a project is beyond the scope of this thesis, but the development of this framework has revealed more about the nature of wellbeing for carers and people living with dementia during the discharge process, and the gaps in practice and availability of evidence.

This research project utilised the Appreciative Inquiry method to consider the changes professionals and carers believe would ensure the wellbeing of people living with dementia and their carers during the discharge process. However, the ‘Dream’ section of the Appreciative Inquiry cycle represents only the fourth section of the process. The wellbeing framework only the fifth section. This research project does not explore the next phases of the cycle which include building on the design phase, and moving into the destiny phase, where a product is co-designed and ultimately implemented and this needs to be addressed in future research.

There is a requirement for research that involves interviews and/or discussions with people living with dementia that considers their perspective of the discharge process, and methods of ensuring their wellbeing. It was not possible due to practical and ethical concerns of the pandemic period to include those living with dementia, but this is a priority for future research in this area. Based on the findings of the systematic review, there is no primary data that involves direct interviews with people with dementia. While this research represents a challenging endeavour, it would not be impossible for a researcher with the right skills and experience of the hospital setting, and interviewing people with dementia. Interviews with people living with dementia have been successfully undertaken previously (Samsi and Manthorpe, 2020). There is a significant research gap in relation to the perspectives of people living with dementia that undermines the evidence available and the acknowledgment of the personhood of individuals with dementia. It is right that their views and perspectives are sought to ensure a discharge process that reflects their needs and perspectives in relation to wellbeing.

The original aim of this research project, in a pre-COVID 19 context, was to undertake an ethnography of the discharge process located on a hospital ward. There is still a requirement for this ethnographic research as observational ward-based projects are few, and there is a need for ethnographic data to reveal what cannot be made visible in an interview medium. Ethnographic data would allow the perspective of people living with dementia, who may not have the ability to take part in an interview to contribute their thoughts and perspectives. An ethnographic study may reveal more about the nature of wellbeing for people living with dementia than this study was able. It was not possible to interview people living with dementia via digital methods, but it would be possible to visually record their discharge journey. The requirement for an ethnographic study is even more vital following the pandemic. Research prior to 2020 does not reflect the changes made to the discharge process due to the pressures wrought by COVID 19. Ethnographic research in the post-COVID 19 era is vital to providing a full visual representation of the discharge process which can aid policy makers and practitioners.

The integration of the findings from this study with the literature available suggested that there is a need for research into the impact of online forums, which are led by carers, focusing on the discharge process and the provision of emotional support. There is also a requirement for research into the admiral nurse role within the discharge process. The positive impact of the admiral nurse role within the discharge process was not identifiable within the literature, although it has been acknowledged elsewhere (Gamble and Dening, 2017; Carter *et al.*, 2018) but was highlighted by participants. Another area which requires further exploration is the specific financial impact of the discharge process on carers of people living with dementia. This is a topic not explored within the literature, but it was identified as a significant consideration by participants which requires further research attention. Furthermore, the necessity for further research into the value of a discharge co-ordinator and a successful format for hospital discharge meetings which provide adequate planning was highlighted within the findings.

The wellbeing framework points to the value of the development of a roadmap of the discharge process aimed at people living with dementia and their carers. How a road map of the discharge process would operate, and what it would consist of, requires extensive further research. A potential focus could involve a participatory action research approach, which would involve both health and social care professionals and carers, and position carers and people living with dementia at the centre of the process. In the next section I will consider the implications for policy makers, clinicians, integrated care boards, charitable bodies and health and social care providers.

12.3 Implications for policy makers, clinicians, integrated care boards, charitable bodies and health and social care providers

12.3.1 Implications for policy makers

This research project has revealed that there is a requirement for policy that focuses on a more sustainable financial and care availability context. Integrated care boards are tasked with providing localised health and social care provision. These bodies must ensure that there are services available that meet the needs of people living with dementia and their carers to enable adequate planning during the discharge process. Services must be available to support wellbeing for carers and people living with dementia in the community and adequate funding must sustain this. Further to this, the findings of this study also call for further integration between community and acute services particularly in relation to admiral nurses.

The analysis of policy documentation in Chapter 3, revealed that there is a need for more transparent and detailed policy guidance in relation to the discharge process and wellbeing, than is currently available and which is updated to reflect the post- pandemic context.

Further detail regarding discharge protocols and clarity regarding the support that should be offered to carers is required, with specific guidance available for people living with dementia. A re-assessment of the discharge to assess model in relation to this carer-dyad should be considered in the post- pandemic period.

12.3.2 Implications for individual NHS Trusts

The analysis of the empirical data collected as part of this study suggests that current policy is not detailed adequately and that further comprehensive policy documentation is necessary (Department of Health and Social Care, 2013; National Institute for Health and Care Excellence, 2015). In response to this, there is a requirement for local NHS Trusts to develop localised policy which responds to some of the gaps evident within the national policy, including the importance of justified risk taking to prioritise wellbeing (National Institute for Health and Care Excellence, 2015). Local NHS Trusts face a challenging proposition tasked with providing wellbeing support to people living with dementia and their carers during the discharge process, with limited clarity concerning how that support should manifest from national policy documentation, and the absence of any new significant funding to ensure this.

12.3.3 Implications for health and social care professionals

The implications of this research project for professionals include- a requirement to promote agency, personal worth and hope for people living with dementia and their carers during the discharge process. This is challenging in a context that is not primarily concerned with wellbeing and in the absence of transparency regarding how to achieve this. Professionals must enable justifiable risk taking that supports the agency of the person living with dementia. Adequate training that incorporates the requirement to avoid bias and stigma when facilitating the discharge process and encourages consideration of wellbeing would be a potential positive outcome based on the findings of this research project.

A potential aid to achieving this goal would be use of the framework to enable wellbeing to be supported during the discharge process outlined within Chapter 9. A re-assessment of the language used, and the emphasis of the discharge process should be considered to prioritise the person living with dementia and their carer. Professionals must also ensure adequate and robust safeguarding of individuals living with dementia and their carer when leaving the hospital. Strong professional accountability for safeguarding during the hospital process should be incorporated further into the process. A training programme such as depicted in the work of Elvish *et al.* (2014) may help facilitate the incorporation of greater emphasis on maintaining wellbeing during this process. Both findings from the empirical data in the findings chapters and the policy outlined in chapter 3 (National Institute for Health and Care Excellence, 2016), discussed the importance of adequate planning and communication, therefore, professionals must centralise discharge planning within their practice.

12.3.4 Implications for charitable bodies

The implications of this research project suggest that charitable bodies should aim to focus resources on providing guidance to carers of people living with dementia in relation to the financial landscape of discharge process. Many charities already offer some financial guidance with resources online and telephone advisory appointments (Alzheimer's Society, 2022). However, the findings of this research project suggest that a service or resource directly focused on the discharge process would be beneficial. Further availability of admiral nurses could be a focus of charitable bodies and signposting to local respite service and groups focused on wellbeing and social activities, including online.

12.3.5 Implications for education

The findings of this thesis have several implications for nursing, medical and allied health education. The importance of making the right decision for the person living with dementia and their carer, at discharge, is evident from the analysis. It has been identified that being confident in one’s ability to make the correct decision is vital to ensuring the right decision is reached (Hagbaghery, Salsali and Ahmadi, 2004). Therefore, increasing education provision in this area is central to ensuring confidence for nurses in their ability to make shared decisions that enable the autonomy of the person living with dementia, and their carer. As mentioned in Chapter 1, there is a need for adult nurses to receive education regarding care planning for people living with dementia and their carers, and in relation to service availability in the community. This should be delivered via a number of different methods including case studies; reflection; virtual scenarios and engaging with lived experts (Cariñanos-Ayala, Arrue and Zarandona, 2022), with the aim of supporting decision making which will sustain the wellbeing of people living with dementia and their carers.

The utility of decision-making aids in supporting clinicians to make the right decisions has been previously identified (Gillespie, 2010). The Situated Clinical Decision-Making framework (Gillespie and Peterson, 2009) posits that focusing on both the context and the requirements of the person being discharged from hospital is vital. Using a decision-making aid such as this may enable nurses and other clinicians to concentrate on supporting the wellbeing of the person living with dementia and their carer, rather than hospital discharge process requirements. Therefore, there is scope for aids, such as these, to feature in nurse and clinical professional education in relation to hospital discharge decision making that supports wellbeing primarily.

In contrast to the argument made above, there is some evidence to suggest that it is organisational and unit contextual factors which impact on, and influence decision making (Nibbelink and Brewer, 2008). The impact of education on decisions made in practice was found to be negligible in both a qualitative study and a systematic review (Thompson and Stapley, 2011; Doherty-King and Bowers, 2013). This would suggest that an educational focus on the discharge process may not impact on practice. However, in direct contrast to this, there is some evidence to show that targeted education specifically related to medication management can improve outcomes at discharge.

Manning *et al* (2007) demonstrated that the use of a medication communication tool at the point of discharge, could improve patient satisfaction with communication connected to medication. This tool includes a section on potential side effects and contraindications. Incorporation of such a tool into clinician education could allow it to be used to aid communication at discharge. Further to this, Cordasco *et al* (2009) demonstrated that a tool aimed at individuals with low literacy levels, or who have English as a second language, was also successful at improving communication at the point of discharge. Therefore, further focus on the incorporation of tools into clinician education may be beneficial.

Participants identified that creating and communicating a discharge plan for the day of discharge was vital. Scotten *et al* (2015) identified that standardising interprofessional communication during the discharge process was central to improving communication and led to higher patient satisfaction levels. Therefore, focusing on improving and clarifying interprofessional communication around the discharge process within the education system, may be an important consideration to improving discharge planning. Wong *et al* (2011) identified that improving the communication skills of clinicians is central to improving discharge outcomes. Therefore, it may be argued that further focus on the importance of communication strategies to support wellbeing, at the point of discharge, is needed within pre-registration courses.

Case based learning has shown to be effective at allowing students to develop the confidence to make the best decisions (Kaddoura, 2011). Developing cases for reflection (Lillyman and Bennett, 2012), focused on the experiences of people living with dementia and their carers and for use in the pre-registration setting, may allow students to develop insight into best practice decision making that is tolerant of risk, whilst developing knowledge, skill and compassion.

In contrast to focusing on the pre-registration environment, Graham, Gallagher and Bothe (2013) identified that the biggest barrier to effective discharge planning and communication is the limited availability of time in the workplace, not the presence or absence of effective education. An answer to this argument is for workplace-based learning, where highly skilled, experienced nurses can coach less experienced nurses in person centred discharge planning (Rahayu, Hartiti and Rofii, 2016). This is with the aim to enable the maintenance of hope, personal worth and agency for both the person living with dementia and their carer. Jantzen (2019) identified that mentor-guides are excellent for facilitating in-context learning. Therefore, the most appropriate form of education related to the findings of this project may be the development of the role of the clinical educator within the hospital setting. This professional role could focus on an inclusive discharge process aiming to support the wellbeing of people living with dementia and their carers. Clinical educators should focus on enabling nurses to promote the agency of people living with dementia and their carers; upholding the value of treating carers as care partners; ensuring person-centred care for people living with dementia and supporting holistic needs.

12.4 Final conclusion

Maintaining the wellbeing of people living with dementia and their carers is vital and acknowledged not only in policy documentation but also in law. Further research regarding how this is achieved in all contexts in required, particularly in the current financial and political climate (Department of Health and Social Care, 2022a; Department of Health and Social Care, 2022b; Department of Health and Social Care, 2022c), and the context of an increasing population of individuals living with dementia. This research project has aimed to develop the evidence base in this area by revealing a potential definition of wellbeing, and detailing the factors that maintain the wellbeing of both carers and people living with dementia during the hospital discharge process. It was evident from the data that proactive health and social care professionals, supportive contexts in relation to both finance and care availability, person- centred care, care that considers the needs of carers beyond just physical considerations and contexts that support risk taking are vital to ensuring wellbeing.

It is hoped that the findings of the research project may contribute to a renewed focus on wellbeing as a central concern within the discharge process. It was argued that small changes in emphasis and framing may enable a shift away from medicalised concerns, and towards more holistic concerns of wellbeing for the carer and person living with dementia. The importance of wellbeing for this patient and carer group cannot be overstated and must be prioritised by clinicians, commissioners, and policy makers. Small changes to language and positioning within the process that might improve wellbeing and the value of these changes should not be underestimated.

Chapter 13. Reference list

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Chapter 14. Appendices

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1 Protocol for study interviewing professionals

What are the factors that ensure the wellbeing of adults living with dementia and their carers during hospital discharge? A qualitative study focused on factors that health and social care professionals identify as integral, to ensuring the wellbeing of people living with dementia and their carers, during the discharge process.

Staff perspectives on the hospital discharge process for people living with dementia being discharged home.

Research ethics committee reference: 4458/2020
Protocol version 4
Date 14/07/2020
Funded by Economic and Social Research Council NINE DTP
Sponsored by: Newcastle University
IRAS: 258329
R&D: 09248

Rationale

Requirement for further research focused on the discharge process in hospital for people living with dementia and their carers.

It is evident that cognitive impairment amongst older adults is one of the key health challenges currently facing the NHS (Alzheimer’s Society, 2016) and over a quarter of hospital beds are occupied by adults with a dementia diagnosis (Alzheimer's Research UK, 2018). The many challenges surrounding living well with dementia impact upon: the NHS; social support services; the housing sector; the UK economy and personally upon individuals themselves. It is therefore, unsurprising that recent governments have focused Department of Health guidance around the challenges of living well with dementia and shaping services in both the acute and community sectors, to suit the needs of this vulnerable and growing demographic of UK society (Department of Health, 2015).

A report by Healthwatch England (2015), highlighted an ongoing concern amongst local community networks regarding the process of hospital discharge, particularly for people living with dementia and their carers. A report by the Alzheimer's Society (2016) into hospital care for people living with dementia, found that poor discharge planning led to both higher re-admission rates and higher levels of nursing or care home admissions following discharge. These outcomes are highly undesirable for patients, carers and the NHS and the report focused on the need for further improvement in the discharge process.

The ability of the discharge planning process to bridge the gap, between the care and support required in hospital and the care required in the community, has also been identified, highlighting the importance of this process in ensuring the wellbeing of people living with dementia and their carers (Bauer *et al*., 2009). Overall, previous studies have not elicited the opinions of healthcare professionals who are ideally placed to advise on ways to ensure the wellbeing of people living with dementia and their carers during the discharge process.

Study design and objectives.

2.1 Aim and Objectives

2.1.1 Aim

The project aims to identify the factors that healthcare professionals identify as integral, to ensuring the wellbeing of patients living with dementia and their carers, during the hospital discharge process (Newcastle upon Tyne Hospitals NHS Foundation Trust).

The research findings will contribute to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing and support needs of this patient and carer group during the discharge process.

Objectives

- To explore the current discharge planning process for people living with dementia and how the needs of patients and carers are identified and addressed.

- To identify what factors work well, during the discharge process and what areas may require further improvement.

- To identify how guidance from ‘Transition between inpatient hospital settings and community or care home settings for adults with social care needs’ (National Institute for Care and Excellence, 2015) and ‘Dementia: assessment, management and support for people living with dementia and their carers’ (National Institute for Care and Excellence, 2018) has been incorporated into hospital discharge practice for adults living with dementia.

- To identify mechanisms to enable health and social care professionals to support people living with dementia and their carers during the hospital discharge process.

- To explore how the COVID-19 pandemic impacted on the hospital discharge process for people living with dementia discharged to their home address and their carers.

2.2 Study design

A qualitative design, which will explore the opinions and perspectives of health and social care professionals involved in the hospital discharge process for people living with dementia and their carers.

Interviews will explore the factors that healthcare professionals identify as integral, to ensuring the wellbeing of patients living with dementia and their carers, during the discharge process. Interview participants will be asked to identify what factors work well during the discharge process and what areas may require further improvement, to improve patient experience. Interviewees will also be asked about the factors that enable them to provide support for wellbeing to both patients and carers. The impact of COVID-19 on the hospital discharge process and the well-being of patients being discharged to their home address and their carers, will also be discussed.

2.3 Site

Interviews with specialist staff based within Newcastle Upon Tyne Hospitals NHS Foundation Trust and across England.

2.4 Participants

Potential health and social care professionals for inclusion:

- Discharge Nurses
- Care Co-ordinators
- Dementia Specialist nurses
- Admiral nurses
- Staff nurses
- Social Workers
- Medical professionals
- Occupational therapists
- Physiotherapists
- Healthcare assistants
- Pharmacists

2.5 Recruitment

Purposive and theoretical sampling methods will be utilised to recruit a sample of health and social care professionals with insight into the hospital discharge planning process. Potential participants will be approached via email and asked to take part in the study. Links are already established between the researchers and the Newcastle Upon Tyne Hospitals Foundation Trust, as a co-supervisor is the Nurse Consultant for Vulnerable Older Adults within the Trust. Many potential participants are already known to the researchers via their professional network.

Other participants from outside the Newcastle Upon Tyne Hospitals Foundation Trust will be contacted via email through Newcastle University researcher professional networks or via the Clinical Research Network. Emergent findings will guide subsequent recruitment. A sample of at least 10-25 participants will be recruited.

2.6 Consent

No participants will lack capacity. Potential participants will be fully informed of the scope of the study and detailed information sheets will be provided to participants. Participants will be given 48 hours at least to decide if they would like to take part and the researcher will ensure that participants are aware that their participation is voluntary and that they may withdraw from the study at any time.

If the participant is happy and willing to go ahead with the interview, the researcher will receive written consent, following a detailed consent discussion, before the interview commences. The researcher will email the consent form in advance and ask that it be completed and sent back in the post. This will be documented.

2.7 Data collection

Interviews will take place via the telephone, Newcastle University licenced Zoom, Teams or Starleaf. If Zoom is the preferred medium of the interviewee, a private meeting with a required code and waiting room will be created. Interviews shall be recorded via voice recorder or zoom record and shall be immediately transferred onto a secure server at Newcastle University. The remaining audio recording will be deleted from the portable audio recorder or zoom account. The consent sheet shall be locked in a secure drawer, only accessible to Laura Prato. Personal data will only be accessed on a secure Newcastle University computer and will be kept on a secure Newcastle University server only accessible to Laura Prato and Dr Clare Abley.

Potential Questions

Describe your role in the discharge process

Describe the discharge process for patients living with dementia and their carers (including the incorporation of guidance from 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs' (National Institute for Care and Excellence, 2015) and 'Dementia: assessment, management and support for people living with dementia and their carers' (National Institute for Care and Excellence, 2018)

How are patient needs identified and addressed (including physical, psychological and social)? What factor help ensure that needs are met?

How are carer needs identified and met (including physical, psychological, social)? What factors help ensure that needs are met?

What would you identify as the best features of the current process?

What do you think could be improved?

How do you think the COVID-19 pandemic has impacted on the well-being of patients living with dementia and their carers during the hospital discharge process?

2.8 Data Analysis

Interviews and observations will be transcribed and analysed using thematic analysis. (Braun and Clarke, 2006). A coding framework will be developed, and themes will be analysed in depth. Qualitative data analysis software (NVIVO 11) will be utilised to manage and retrieve data.

2.9 Duration

Data collection and analysis shall continue for approximately 24 months commencing October 2020

Responsibilities and programme management

3.1 Sponsor:

Newcastle University.

3.2 Programme Management:

The Chief Investigator (CI) has overall responsibility for the delivery of this study. As the researcher (Ms Laura Prato) is a PhD student at Newcastle University, Dr Clare Abley will oversee the study as CI, due to her previous experience as a PI and NIHR Clinical Academic Training Lectureship holder.

3.3. PPI:

A patient and participant involvement group of carers for adults living with dementia have been integral in the design of this study. The researcher (Ms Laura Prato) has also consulted with a group of discharge nurses, nurse consultants, specialist dementia nurses, care-co-ordinators and social workers in the design of the study.

3.4 Research Governance:

Research Governance approval will be sought from the Newcastle Upon Tyne Hospitals NHS Foundation Trust and Caldicott approval shall be sought. The researcher (Ms Laura Prato) will be involved in data collection and will apply for a research passport, referring specifically to access for this study. The CI (Dr Clare Abley) has access to staff and patient data as part of her substantive contract as a nurse consultant employed by Newcastle Upon Tyne Hospitals NHS Foundation Trust. As the researcher (Ms Laura Prato) is a PhD student, insurance will be provided by the sponsor, Newcastle University. The CI (Dr Clare Abley) will be provided for, as part of her substantive contract of employment. Both researchers have completed Good Clinical Practice Training within the last three years.

3.5 Safety:

The safety of both researchers will be ensured by adhering to relevant Newcastle Upon Tyne Hospitals NHS Foundation Trust and Newcastle University policies.

2 Protocol for study interviewing carers

Ensuring well-being for people living with dementia and their carers following hospital discharge

A qualitative study exploring how to ensure the well-being of people living with dementia and their carers, during and after the hospital discharge process.

Protocol version 3
Date 13/01/2021
Funded by Economic and Social Research Council NINE DTP
Sponsored by: Newcastle University
IRAS: 287679

Rationale

Requirement for further research focused on the hospital discharge process and immediate period of return to the community for people living with dementia and their carers.

It is evident that cognitive impairment amongst older adults is one of the key health challenges currently facing the NHS (Alzheimer’s Society, 2016) and over a quarter of hospital beds are occupied by adults with a dementia diagnosis (Alzheimer's Research UK, 2018). The many challenges surrounding living well with dementia impact upon the NHS; social support services; the housing sector; the UK economy and personally upon individuals themselves. It is therefore, unsurprising that recent governments have focused Department of Health guidance around the challenges of living well with dementia and shaping services in both the acute and community sectors, to suit the needs of this vulnerable and growing demographic of UK society (Department of Health, 2015). The impact of the recent COVID 19 pandemic further intensifies the need for an abundance of appropriate and proportionate support mechanisms.

A report by Healthwatch England (2015), highlighted an ongoing concern amongst local community networks regarding the process of hospital discharge, particularly for people living with dementia and their carers. A report by the Alzheimer's Society (2016) into hospital care for patients with dementia, found that poor discharge planning led to both higher re-admission rates and higher levels of nursing or care home admissions following discharge. These outcomes are highly undesirable for patients, carers and the NHS and the report focused on the need for further improvement in the discharge process and the support available for carers and patients immediately following hospital discharge.

The ability of the discharge planning process to bridge the gap, between the care and support required in hospital and the care required in the community, has also been identified, highlighting the importance of this process in ensuring the well-being of people living with dementia and their carers (Bauer *et al*., 2009). The impact of COVID- 19 on the hospital discharge process and the immediate period of return into the community, for people living with dementia and their carers, is unknown. Further information relating to the process must be collected to ensure that people living with dementia and their carers are receiving the correct support during this pandemic and beyond.

Study design and objectives.

2.1 Aim and Objectives

2.1.1 Aim

The study will address the holistic well-being of people living with dementia and their carers during the discharge from hospital planning process and during the period of return to the community before, during and after the COVID- 19 pandemic. The project aims to identify the physical, social and emotional wellbeing (Department of Health, 2010) and support needs of carers and patients during and immediately after, the process of discharge, through a qualitative investigation of the hospital discharge process.

The research findings will contribute to the developing evidence base available to policy makers and clinical professionals, in relation to the well-being and support needs of this patient and carer group during the hospital discharge process and return to the community before, during and after the COVID-19 pandemic period.

Objectives

- To identify what support in relation to wellbeing (physical, emotional, social) carers and patients received during and after the hospital discharge process and whether this could be improved through a series of qualitative interviews.

- To identify support mechanisms and interventions which could be beneficial in promoting wellbeing during the discharge planning process and following discharge in the community through a series of qualitative interviews.

- To consider the potential barriers and facilitators to maintaining health and well-being during the leaving hospital process and in the community through a series of qualitative interviews.

2.2 Study design

A qualitative design, which will explore the opinions and perspectives of the carers of individuals living with dementia in relation to well-being for carers and individuals living with dementia during this hospital discharge process and on return to the community. The study will also explore the perspectives of volunteers in the community, who support people living with dementia and their carers.

Interviews with carers will explore whether patient and carer physical, social and emotional needs were addressed during the discharge process and what factors support well-being on return to the community. Alongside this, interviews will aim to identify support systems that would be beneficial in promoting well-being, during the discharge planning process and following discharge into the community.

Questions will explore- what support carers and patients have received during the hospital discharge process and whether this could be improved; whether carers have been adequately involved in and prepared emotionally and practically for their relatives discharge; an examination of existing community support networks and a consideration of the potential opportunities and challenges to maintaining physical health and well-being during and post-discharge.

Potential interview questions include:

What support (emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What could have been improved or helped you to feel more supported?

Did you feel adequately involved in the discharge process?

Did you feel prepared emotionally and practically for the discharge of your relative/friend?

What support do you have available to you in the community?

What support has helped you to maintain your physical and emotional well-being following your relative/friend's hospital discharge?

Has anything acted as a barrier to you maintaining your physical and emotional well-being following your relative's discharge?

How do you think COVID-19 has impacted on your experience?

What does well-being mean to you?

Interviews with volunteers will explore what support is available for carers of people living with dementia and the individuals themselves, following discharge from hospital into the community.

Potential questions:

- How do you/your organisation support the well-being of carers and individuals living with dementia after hospital discharge?

- What do you think are the main challenges to supporting well-being in the community immediately following hospital discharge?
- How do you think COVID 19 has impacted on the well-being of carers and individuals living with dementia during the hospital discharge process and following discharge into the community?

2.3 Site

Interviews with carers of people living with dementia and volunteers will be across the UK.

2.4 Participants

Inclusion criteria carers

Carers of people living with dementia who have been discharged from hospital in the last 3 years.

Carers who are related or unrelated to the person living with dementia and currently providing care for the person living with dementia (no set time period required).

Carers will be self-identifying, and the definition of carer will include all aspects of the caring role including physical, emotional, social, and organisational caregiving.

Carers must be over the age of 18 as the focus of the study is not on the role and experience of young carers.

Carers must be based in the UK.

Exclusion criteria carers

A carer under the age of 18

Relatives, friends, and family members who are not involved in the carer role.

Individuals who lack capacity (under the Mental Capacity Act (2005) and are unable to give informed consent.

Inclusion criteria volunteers

Volunteers who support people living with dementia and their carers in the community.

There is no set period that an individual has to have been a volunteer to qualify for inclusion in the study.

Volunteers must be based in the UK.

Exclusion criteria volunteers

Domiciliary care workers who are not in a voluntary role (this does not exclude individuals receiving carers allowance)

Individuals who lack capacity (under the Mental Capacity Act (2005) and are unable to give informed consent.

Individuals who live or provide care outside the UK.

2.5 Recruitment

Carers and volunteers will be recruited via social media and voluntary organisation mailing lists. Examples of these organisations include the Newcastle Elders Council and Dementia Matters. A sample of at least 20 carers will be recruited and 10 volunteers.

2.6 Consent

No participants will lack capacity. Potential participants will be fully informed of the scope of the study and detailed information sheets will be provided to participants via email or the post.

Participants will be given 48 hours at least after receiving the information sheets to decide if they would like to take part in the consent discussion. Laura Prato will ensure that participants are aware that their participation is voluntary and that they may withdraw from the study at any time.

Laura Prato will organise a detailed consent discussion (ensuring that the participant understands the scope, format and demands of the research) with the potential participant via phone, Teams or Zoom in advance of the interview. The confidentiality protocol will also be supplied to the potential participant to ensure they are aware of the occasions and circumstances where confidentiality may be broken.

At the end of the consent discussion, Laura Prato will receive informed consent, if the participant decides to take part in the research study and sign the consent form either electronically or via traditional wet signature. Laura Prato will wait until the consent form is emailed or sent via the post and will sign the form herself. After this has occurred, Laura Prato will arrange a date and time for the interview to take place.

Before the interview commences, Laura Prato will verbally check that the participant still wishes to take part in the research. This will be checked again at the end of the interview. If at any point the participant seems unhappy to continue the interview or is distressed during the interview, Laura Prato will again check that the participant is happy to answer the interview questions. This will be documented. At the end of the interview, Laura Prato will offer a wellbeing resource sheet to the participant if they request one and signpost them to their GP if this is necessary.

2.7 Data collection

Interviews will take place via the telephone, zoom or teams. Interviews shall be recorded via audio or video and shall be transferred onto a secure server at Newcastle University. The remaining audio recording will be deleted from the portable audio recorder. The recording will be deleted 3 months after the end of the study (approximately February 2023). The consent sheet shall be locked in a secure drawer on secure premises, which is only accessible to the researcher. Once practicable the consent form shall be transferred to Newcastle University premises. If the consent form is signed digitally, it will be stored on secure university systems. Personal data will only be accessed via a secure Newcastle University server only accessible to Laura Prato.

2.8 Data Analysis

Interviews will be transcribed and analysed using thematic analysis. (Braun and Clarke, 2006). A coding framework will be developed, and themes will be analysed in depth. Qualitative data analysis software (NVIVO 11) will be utilised to manage and retrieve data.

2.9 Duration

Data collection and analysis shall continue for approximately 24 months commencing December 2020

Responsibilities and programme management

3.1 Sponsor

Newcastle University.

3.3. PPI

A patient and participant involvement group of carers for people with a dementia diagnosis have been integral in the design of this study. The researcher (Ms Laura Prato) has also consulted with a group of discharge nurses, nurse consultants, specialist dementia nurses, care-co-ordinators and social workers in the design of the study.

3.4 Research Governance

As the researcher (Ms Laura Prato) is a PhD student, university professional liability insurance will ensure indemnity alongside indemnity provided by the sponsor. The CI and PI (Dr Clare Abley) will be provided for, as part of her substantive contract of employment. Both researchers have completed Good Clinical Practice Training within the last three years.

3.5 Data Management and GDPR

The researcher will follow the Data Protection Act 2018 and GDPR principles and ensure the anonymisation of all data. Participants will be issued a unique identifying number and personal information will be kept on one electronic document via Newcastle universities secure server only.

Personal information will be deleted at the end of the study.

Anonymised data will be kept on secure servers at Newcastle University. At the conclusion of the the research study, the data provided will be de-identified and made available as “open data” through a research data repository once the study has concluded [https://www.ukdataservice.ac.uk/deposit-data.aspx). This means the de-identified study data will be publicly available and may be used for purposes not related to this study. The data will be available indefinitely. It will not be possible to identify participants from the “open data”.

3.5 Confidentiality Protocol and Distress Protocol

During the interview process, the researcher will utilise the confidentiality and distress protocol to protect both participant and the researcher wellbeing. The steps outlined in the confidentiality protocol will guide Laura Prato in situations where breaking confidentiality is required to safeguard participants, the researcher, and other vulnerable adults. The actions to be taken in the event of the requirement to break confidentiality are included below in section 4. The distress protocol to be followed during the interview is included in section 5.

4 Confidentiality Protocol

4.1 Requirement to break confidentiality following an interview.

4.1.1 General points

Laura Prato will discuss the potential need to break confidentiality in accordance with the confidentiality protocol, as part of the consent discussion.

If an immediate threat of harm emerges during the consent discussion or the interview, Laura Prato will alert the relevant authority/emergency service (Police/Ambulance). If the threat is not immediate, Laura Prato will advise and encourage the participant to contact the relevant authority/service.

If a safeguarding issue arises, Laura Prato will follow local policy and procedures for safeguarding vulnerable adults. She will also inform the PI (Clare Abley) and the study sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University.

If Laura Prato requires support, in relation to her own wellbeing outside of the supervision team, this is available via the mental health and wellbeing team based at Newcastle University.

4.1.2 Specific Actions

The following specific actions will be taken if necessary:

1) Participant says something that indicates suicidal thoughts e.g. ‘life so bad it’s not worth living’

Laura Prato will follow recommendations from the Samaritans and allow the participant to talk about their thoughts, determining whether immediate assistance or support is required.

https://www.samaritans.org/how-we-can-help/if-youre-worried-about-someone-else/supporting-someone-suicidal-thoughts/

If immediate support is required Laura Prato will ring the emergency services and request an ambulance, staying with the individual and providing support until the ambulance arrives. The study PI, Dr Clare Abley will be informed. The incident will be reported to the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University.

If immediate intervention is not considered necessary, Laura Prato will signpost the participant to their GP and / or other community support services e.g. Alzheimer's Society, Mind. Laura Prato will contact the participant the day after the interview (if the participant consents to this) to offer further support. Laura Prato will discuss the incident with the PI, including any further action required.

2) Refusal of participant to inform the police of illegal activity.

If a participant discloses illegal activities and following advice from Laura Prato, refuses to inform the police, Laura Prato will contact the police. Laura Prato will inform Dr Clare Abley, the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University, of this incident.

3) Disclosure of adult abuse by a carer/relative/volunteer.

Adult abuse can take a wide range of forms (physical abuse; domestic violence/abuse; sexual abuse; psychological/emotional abuse; financial/material abuse; modern slavery; discriminatory abuse; organisational/institutional abuse; neglect or acts of omission; self-neglect). If adult abuse is disclosed during an interview, Laura Prato will follow local safeguarding policy and procedures and make a safeguarding referral. The PI and the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University, will be informed.

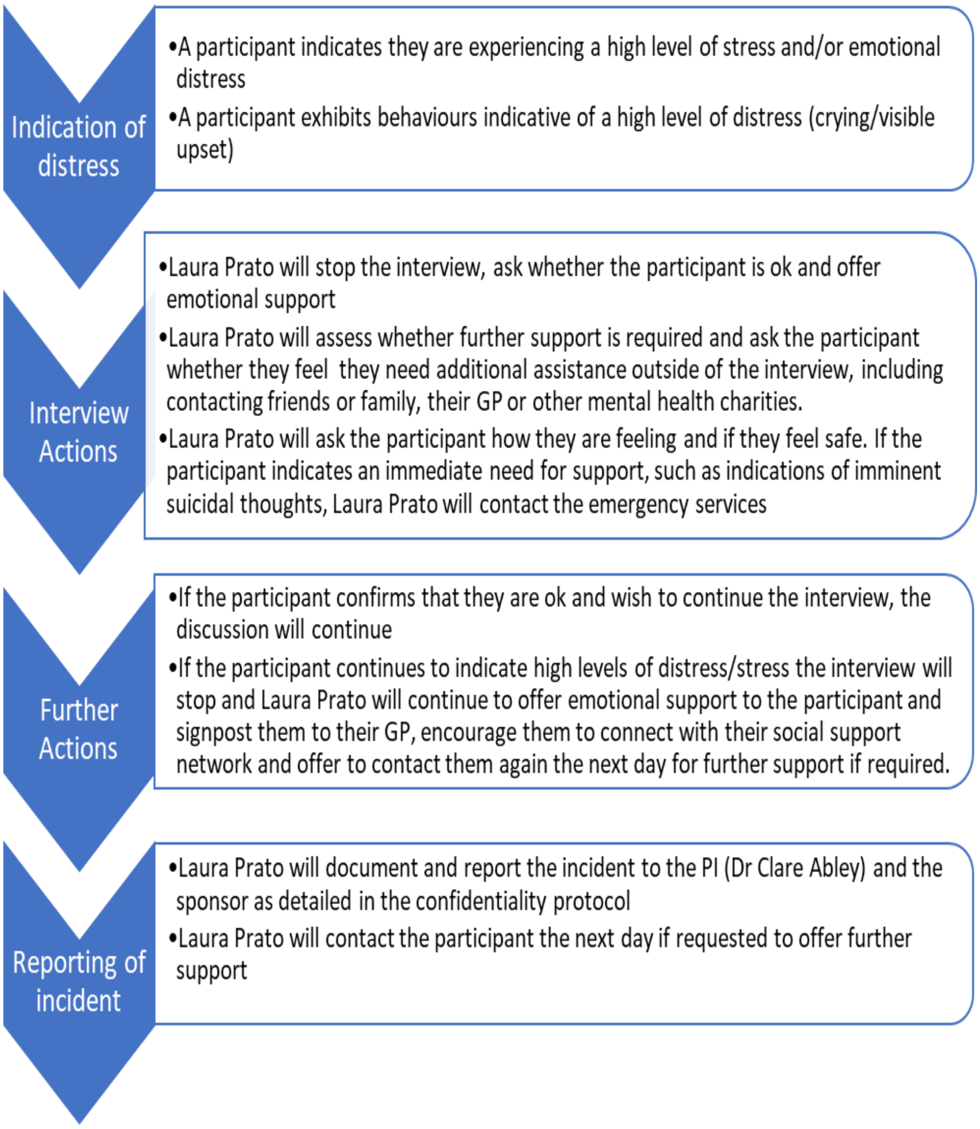
Laura Prato will contact Dr Clare Abley in the first instance if uncertain whether confidentiality should be broken. If required, further advice will be sought from the wider supervision team, which includes Professor Thomas Scharf, Professor Yvonne Birks and Dr Joy Adamson, and from the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research, at Newcastle University.

5 Distress Protocol

(Draucker, Martsolf & Poole, 2009)

Adapted from Draucker, Martsolf & Poole (2009) available at https://www.mmu.ac.uk/media/mmuacuk/content/documents/rke/Advisory-Distress-Protocol.pdf.

If during an interview, Laura Prato identifies that the participant is experiencing severe distress, she will follow the steps outlined in the diagram below:



Indication of distress

- A participant indicates they are experiencing a high level of stress and/or emotional distress
- A participant exhibits behaviours indicative of a high level of distress (crying/visible upset)

Interview Actions

- Laura Prato will stop the interview, ask whether the participant is ok and offer emotional support
- Laura Prato will assess whether further support is required and ask the participant whether they feel they need additional assistance outside of the interview, including contacting friends or family, their GP or other mental health charities.
- Laura Prato will ask the participant how they are feeling and if they feel safe. If the participant indicates an immediate need for support, such as indications of imminent suicidal thoughts, Laura Prato will contact the emergency services

Further Actions

- If the participant confirms that they are ok and wish to continue the interview, the discussion will continue
- If the participant continues to indicate high levels of distress/stress the interview will stop and Laura Prato will continue to offer emotional support to the participant and signpost them to their GP, encourage them to connect with their social support network and offer to contact them again the next day for further support if required.

Reporting of incident

- Laura Prato will document and report the incident to the PI (Dr Clare Abley) and the sponsor as detailed in the confidentiality protocol
- Laura Prato will contact the participant the next day if requested to offer further support

3 Participant information sheet carers

Staff perspectives on the hospital discharge process for patients living with dementia being discharged home.

Participant Information Sheet

You are invited to take part in an important research study taking place within the Newcastle Upon Tyne Hospitals NHS Foundation Trust. Before you decide we would like you to understand why the research is being done and what it would involve for you. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1. Purpose of the study and what taking part involves.

This study is investigating the hospital discharge process for older patients living with dementia within Newcastle Hospitals Trust inpatient services.

A significant proportion of older people who are admitted to general hospitals and subsequently discharged will have problems with memory and cognition. In spite of this, little research has been done to explore their experiences or their carers' experiences, during the discharge process. Additionally, we know very little of the staff perspectives on the hospital discharge planning process for patients living with dementia and their carers.

This study seeks to gain a fuller understanding of the staff perspective on:

- Current practice of the discharge process for patients living with dementia who are being discharged home.
- How the needs of these patients and their carers are identified and addressed.
- How the COVID-19 pandemic has impacted upon the hospital discharge process and patient and carer well-being.
- How practice might be improved.

This information will be used to help improve the discharge process for future patients living with dementia and their relatives.

How can you be involved?

We appreciate that clinical staff have many demands on their time; however, we very much hope you will see the value in sharing your practice and experiences with us. For this research Laura Prato (ESRC funded PhD research student and RGN) would like to conduct research interviews with health and social care staff, involved in the provision of care to older inpatients living with dementia and their relatives during the hospital discharge process. Interviews will last no longer than one hour and will be held at a time that is most convenient to you. Interviews will take place either over the phone, starleaf, teams or zoom. We will seek your permission to audio record the interview or video record over zoom. The transcript of this interview will be fully anonymised, so that you cannot be identified.

It is entirely up to you to decide whether or not to take part in any aspect of this study.

What are the possible benefits of taking part?

Taking part in this study will give you the opportunity to express your opinions about the hospital discharge process for older adults living with dementia. You will also be able to share your experiences of caring for these patients and their carers / relatives, with an interested researcher. The material gathered for this study will generate an evidence base that can be used to positively shape future hospital discharge procedures for older people living with dementia.

What are the possible disadvantages of taking part?

The researcher, Laura Prato, will make every effort to be respectful during the interview. If you do not wish to take part in the interview or answer a particular question, you are free to leave at any time.

What if I don’t want to carry on with the study?

You are free to withdraw from the study at any time, without giving a reason. This will not affect your work life in anyway.

What if the researchers come across bad practice or harm to individuals?

In the unlikely event that any disclosures of bad practice or harm to individuals become apparent during the study, we will follow Trust Safeguarding Policies and Procedures.

Part 2. Further study information

What will happen to the results of the study?

This study will identify a wide range of staff perspectives on the hospital discharge process for older patients living with dementia. Summaries of the research findings will be published in academic journals; professional publications relating to Nursing and Social Care and, where appropriate local newsletters. All data will be anonymised, so that participants cannot be identified in any outputs from the research.

Anonymised data and identifying data will be kept on secure servers at Newcastle University and will not be accessible to anyone other than Laura Prato and her supervisory team. The study and data may be audited by Newcastle Upon Tyne Hospitals NHS Foundation Trust. Identifying data will be destroyed at the end of the study. Anonymised data will be destroyed in 5 years' time.

Who is doing the research and in what capacity?

The Chief Investigator for this project, Dr Clare Abley, is a Nurse Consultant for Vulnerable Older Adults employed by The Newcastle upon Tyne Hospitals NHS Foundation Trust. Since 2011, her work has focused upon improving acute hospital care for older people experiencing problems with memory and thinking.

Laura Prato is a Nurse and PhD student at Newcastle University. Her previous projects have focused upon the hospital experience of older adults with problems with memory and thinking.

Laura will be supported through the research according to Newcastle University processes including a thesis advisory team and will have additional supervision from Professor Joy Adamson (a methodologist in health research) Professor Thomas Scharf (a specialist in qualitative research) and Professor Yvonne Birks (providing expertise in health and social care).

Funding and ethical review

This project is funded by the Economic and Social Research Council. The study has been approved by the Newcastle University Ethics Committee, the NHS Health Research Authority and R&D at Newcastle Upon Tyne Hospitals NHS Foundation Trust.

Getting in touch

If you have any questions about the research either now or later, please contact:

- Laura Prato (email:

If you wish to complain formally, you can do this through the NHS Complaints Procedure. Details of how to complain can be obtained from the hospital.

General Data Protection Regulations

We will need to use information from you for this research project.

This information will include your name, email address and job title. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?

You can find out more about how we use your information

at www.hra.nhs.uk/information-about-patients/

or by asking one of the research team (Ms Laura Prato)

or by sending an email to (Data Protection Officer for Newcastle University)

4 Participant information sheet professionals

Ensuring wellbeing for people living with dementia and their carers following hospital discharge.

You are invited to take part in a research study on the well-being of people living with dementia and their carers when returning home from hospital. Before you decide whether you wish to take part we would like you to understand why the research is being done and what it would involve for you. Part 1 tells you the purpose of this study and what it will involve if you decide to take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1. Purpose of the study and what taking part involves.

This study is investigating what happens when people living with dementia return home from hospital and what support is available within the community.

Many older people who are admitted to general hospitals and then discharged have problems with memory and cognition. Despite this, little research has been done to explore their and their carers' experiences after returning home from hospital. The impact of COVID-19 measures on the hospital discharge process and on the support available in the community is unknown.

This study seeks to gain a fuller understanding of:

- The community support available for people living with dementia and their carers.
- Opportunities and challenges to supporting wellbeing in the community immediately following hospital discharge.
- How COVID-19 has impacted on the hospital discharge process and available community support.

The information collected in this study will be used to help identify how the discharge process can be improved for people living with dementia and their carers. It will also be used to identify potential support mechanisms available within the community.

How can you be involved?

For this research, Laura Prato (an ESRC-funded PhD research student) would like to interview carers or relatives of people living with dementia in the community about their experiences of the hospital discharge process. Laura is also interested in your views on the discharge experience of the person you care for/your relative and your opinions on the support available in the community following hospital discharge.

Laura Prato is specifically seeking individuals over the age of 18 who would self-identify as a carer in any capacity including but not limited to emotional, social, physical, and organisational care. This does not include paid domiciliary care workers but does include individuals receiving carers allowance.

Interviews will last no longer than one hour and will be held at a time that is most convenient to you. Interviews will take place via telephone or Zoom or Teams. An informed consent discussion will take place before the interview on a separate occasion. This will be arranged for a time and date of your convenience. During this discussion we will talk about what taking part in the study entails, the potential benefits and disadvantages of taking part and the questions that will be asked. We will also discuss your right to not answer any questions or withdraw from the study at a later date. Further, we will discuss the confidentiality protocol and occasions when confidentiality may be broken.

If at the end of the discussion you wish to go ahead with the interview, the consent form will be signed and returned to Laura Prato electronically or via the mail. Once Laura Prato has received the consent form, a date and time for the interview will be finalised. The interview will not take place until Laura Prato has received the consent form. Before the interview, Laura Prato will ask you to confirm that you still give consent to take part in the interview and will ask again at the end of the interview. If at any point during the interview you become distressed, Laura Prato will ask whether you wish to continue. You may stop the interview at any time. We will seek your permission to audio or video record the interview. Recordings will be deleted 3 months after the end of the study (approximately February 2023). Interview transcripts will be anonymised, so that you cannot be identified. Recordings will not be anonymised but will only be accessible to Laura Prato or the supervisory team.

If you wish, a summary of the interview transcript will be sent to you following the interview.

It is entirely up to you to decide whether you wish to take part in this study.

What are the possible benefits of taking part?

Taking part in this study will give you the opportunity to express your views about the support available during the hospital discharge process and in the community for people living with dementia and their carers. You will also be able to share your experiences of being a carer/relative at this time, with interested researchers. The material gathered for this study will contribute to evidence surrounding improving hospital discharge procedures and community support mechanisms, for people living with dementia and their carers.

What are the possible disadvantages of taking part?

It is possible that you may feel distress during or after the interview. You may also find the interview inconvenient.

The researcher, Laura Prato, will respect your wishes during the interview and try to limit any distress caused by taking part. You should only answer questions or discuss topics that you wish to. If you do not wish to take part in the interview or answer a particular question, you are free to end the interview at any time. Laura Prato will provide you with a resource sheet of organisations that can provide wellbeing support following the interview if you wish.

Laura Prato will arrange the interview and consent discussion for times that are convenient for yourself.

What if I don’t want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason until 6 months after the interview.

Will my personal information remain confidential?

Please note that your personal details (email/address/phone number) will always be kept confidential and will only be known by the researcher (Laura Prato). The data you provide during the interview will be anonymised and you will not be identifiable, nor will any person or place you discuss during the interview.

What if the researcher identifies malpractice or harm to individuals?

Please be aware that the researcher (Laura Prato) has a duty of care to disclose personal information to the relevant authorities (Police or other emergency services) if during the course of the interview she becomes aware of a risk of harm to yourself or someone close to you.

If you disclose an intention or knowledge of harm to yourself or others, the researcher has a moral, and potentially legal obligation to break confidentiality to protect you or others and to inform Dr Clare Abley as the Chief investigator.

This would also be the case if you disclose information regarding participation in illegal activities.

Also, if during an interview there is an immediate risk of self-harm, Laura Prato will ring an ambulance to safeguard your wellbeing.

If during an interview you indicate feelings of depression, Laura Prato will signpost you to your GP, support network and other support services offered by community groups such as Alzheimer's UK and/or Mind. Laura Prato will seek your permission to contact you the day following the interview to offer further support.

If you disclose illegal activities during an interview, Laura Prato will inform the police.

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If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral.

Part 2. Further study information

What will happen to the results of the study?

Summaries of the research findings will be published in academic journals, professional publications and, where appropriate, local newsletters. All information collected will be anonymised, so that participants cannot be identified in any outputs from the research.

Anonymised data will be kept on secure servers at Newcastle University and will not be accessible to anyone other than Laura Prato and her supervisory team until the end of the study.

If you agree to take part in the research study the data provided will be de-identified and made available as "open data" through a research data repository once the study has concluded [https://www.ukdataservice.ac.uk/deposit-data.aspx). This means the de-identified study data will be publicly available and may be used for purposes not related to this study. The data will be available indefinitely. It will not be possible to identify you from the "open data".

Who is doing the study and in what capacity?

This research is being undertaken by Laura Prato who is a nurse and PhD student at Newcastle University. Her previous projects have focused on the hospital experience of older patients with memory and thinking problems.

Laura will be supported by her PhD supervisory team:

- Professor Thomas Scharf Professor of Social Gerontology, Newcastle University
- Professor Joy Adamson, University of York
- Professor Yvonne Birks, University of York

- Dr Clare Abley, Nurse Consultant for Vulnerable Older Adults at The Newcastle upon Tyne Hospitals NHS Foundation Trust and Honorary Clinical Senior Lecturer Newcastle University

The chief investigator for this project is Dr Clare Abley.

Funding and ethical review

This PhD is funded by the Economic and Social Research Council. The study has been approved by relevant ethics committees.

Getting in touch and complaints

If you have any questions about the research either now or later, please contact:

-

If you have any complaints, concerns or comments about the research, please email: to discuss your concerns.

General Data Protection Regulations

Newcastle University will be using information from you in order to undertake this research study and will act as the data controller for this study. This means that Newcastle University is responsible for looking after your information and using it properly. When we use personally-identifiable information from people who have agreed to take part in research, we ensure that it is in the public interest. Your rights to access, change or move your information are limited, as Newcastle University needs to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study after 6 months, Newcastle University will keep the information about you that has already been obtained. To safeguard your rights, the minimum personally-identifiable information will be used. You can find out more about how Newcastle University uses your information at https://www.ncl.ac.uk/data.protection/dataprotectionpolicy/privacy notice/ and/or by contacting Newcastle University's Data Protection Officer.

We will use your name and contact details [telephone number, email and address] to contact you about the research study. Individuals at Newcastle University may look at your research data to check the accuracy of the research study. The only individuals at Newcastle University who will have access to information that identifies you will be individuals who need to contact you [Ms Laura Prato or Dr Clare Abley] or audit the data collection process.

If you agree to take part in the research study, information provided by you may be shared with researchers running other research studies at Newcastle University and in other organisations. These organisations may be universities or NHS organisations. Your information will only be used by organisations and researchers to conduct research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research and cannot be used to contact you. It will not be used to make decisions about future services available to you.

5 Topic guide carer interviews

TOPIC GUIDE

- Could you just describe a little bit your overall experience of your wife/husband/mum/dad leaving hospital?
    - What support (Emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What could have been improved or helped you to feel more supported?
    - Did you feel adequately involved in the discharge process?
    - What went well during the discharge process?
    - What could have gone better?
    - Did you feel prepared emotionally and practically for the discharge of your relative/friend?
    - What support do you have available to you in the community?
    - What support has helped you to maintain your physical and emotional well-being following your relative/friend's hospital discharge?
    - Has anything acted as a barrier to you maintaining your physical and emotional well-being following your relative's discharge?
    - How do you think COVID-19 has impacted on your experience?
    - What does well-being mean to you?

6 Consent form carers

CONSENT FORM FOR CARERS / RELATIVES

Ensuring wellbeing for people living with dementia and their carers following hospital discharge

I…………………………………………………………………….
. **(name)**

Please initial each

I have read the information sheet (version 3) dated 18/12/2020 giving details of this study, have been given a copy to keep and have had the opportunity to ask questions of the researcher. ☐

I understand that my participation is voluntary, and I can withdraw consent at any time, without giving any reason up until 6 months after my interview. ☐

I understand that this consent form and the data collected during the study may be looked at by individuals regulatory or ethical authorities, where it is relevant to my taking part in research. ☐

I give permission for information about me to be held by Newcastle University. I understand that records will be confidential and will be stored securely on systems within the University. ☐

I understand that interviews will take place via zoom, teams or telephone and I give permission for a video ☐

recording or an audio recording to be taken. I understand that only Ms Laura Prato and the supervisory team will view the video or listen to the audio of the interview.

I understand that anonymous extracts from the interviews may be used in disseminating the project findings. ☐

I understand that if I tell you something that suggests that someone is at risk, or illegal activities are taking place, you will inform the appropriate authorities as detailed within the confidentiality protocol. You will alert the Chief investigator (Dr Clare Abley) and the Sponsor (Newcastle University) of the confidentiality breach. ☐

If I indicate intentions of immediate self-harm, I understand that Laura will ring an ambulance to safeguard my wellbeing. ☐

If during an interview I indicate feelings of depression, Laura Prato will contact me the day after the interview to offer further support. ☐

If I disclose illegal activities during an interview, Laura Prato will inform the police. ☐

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If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral. ☐

I would/would not like a typed summary of the interview sent to me. ☐

I understand and give permission/do not give permission for researchers in the future to access the anonymous data provided for further research purposes. ☐

I understand and agree for anonymised data to be made available as “open data” through a research data repository once the study has concluded. ☐

☐

I consent to take part in this study and I understand that it entails voluntary interviews with the researcher Ms Laura Prato.

Signed... ………
Date...............................

Print name..

Consented by ……………………............... (signed)
Date...............................

Print name

....

7 Consent form professional participants

Staff perspectives on the hospital discharge process for patients living with dementia being discharged home.

I
(name)

of……………………………………………………………… …………………… **(Staff Role)**

I have read the information sheet which outlines the details of this study, have been given a copy to keep and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and I can withdraw consent at any time without giving any reason and without my legal rights being affected. ☐

I understand that this consent form and any data collected during the study may be looked at by individuals from the research sponsor or from regulatory or ethical authorities, where it is relevant to my taking part in research. ☐

I give permission for information concerning my details to be held by Newcastle University. I understand that records will be confidential and will be stored securely on systems within the University. I also give permission for further, future research involving the anonymous data provided. ☐

I understand that anonymous extracts from research recordings and notes may be used in disseminating the project findings. ☐

I understand that if I tell you something that suggests someone is at risk, you will inform the appropriate person, according to Newcastle Upon Tyne Hospitals NHS Foundation Trust safeguarding policy. ☐

I give permission for the interview to be recorded via the zoom record function or audio recorder. ☐

I consent to take part in this study. ☐

Signed... ....
Date..............................

Consented by................................... (signed)
Date..............................

Print name..

8 Confidentiality protocol

Thank you for agreeing to take part in this research project.

Please note that your personal details (email/address/phone number) will always be kept confidential and will only be known by the researcher (Laura Prato). The data you provide during the interview will be anonymised and you will not be identifiable, nor will any person or place you discuss during the interview.

Provisions for disclosing confidential information.

Please be aware that the researcher (Laura Prato) has a duty of care to disclose personal information to the relevant authorities (Police or other emergency services) if during the course of the interview she becomes aware of a risk of harm to yourself or someone close to you.

If you disclose an intention or knowledge of harm to yourself or others, the researcher has a moral, and potentially legal obligation to break confidentiality to protect you or others.

This would also be the case if you disclose information regarding participation in illegal activities.

The researcher (Laura Prato) will discuss the need to break confidentiality with you and ask that you seek the relevant support if you disclose an intention or knowledge of harm to yourself and/or others.

Also, if during an interview there is an immediate risk of self-harm, Laura Prato will ring an ambulance to safeguard your wellbeing.

If during an interview you indicate feelings of depression, Laura Prato will signpost you to your GP, support network and other support services offered by community groups such as Alzheimer's UK and/or Mind. Laura Prato will seek your permission to contact you the day following the interview to offer further support.

If you disclose illegal activities during an interview, Laura Prato will inform the police.

If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral.

The researcher will alert Dr Clare Abley (supervisor) and the study sponsor representative and the Dean of Translational and Clinical Research at Newcastle University of the circumstances of the breach of confidentiality for safeguarding purposes and this will be documented.

On request, the researcher (Laura Prato) will provide you with a list of potential support options following the interview if you wish to seek further well-being support.

9 Health Research Authority approval

Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Dr Clare Abley
Campus for Ageing and Vitality Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk
02 September 2020

Dear Dr Abley

What are the factors that ensure the well being of adults living with dementia and their carers during hospital discharge? A qualitative study focused on factors that health and social care professionals identify as integral, to ensuring the well being of patients living with dementia and their carers, during the discharge process

258329
19/HRA/4265
Organization not set

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **258329**. Please quote this on all correspondence.

Yours sincerely,

Email: approvals@hra.nhs.uk

Copy to: **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

10 REC ethical approval

Northwest - Greater Manchester West Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

08 February 2021

Dr Clare Abley
Campus for Ageing and Vitality
Westgate Road
Newcastle Upon Tyne
NE4 6BE

Dear Dr Abley,

Title: Ensuring well-being for people living with dementia and their carers following hospital discharge A qualitative study addressing the physical, social and emotional requirements of patients living with dementia and their carers during and after the hospital discharge process.

REC Reference: 20/NW/0420

IRAS: 287679

Thank you for your submission on 28 January 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, ‘clinical trials’ are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improvingresearch/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improvingresearch/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/applicationsummaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19.
In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at:
https://www.hra.nhs.uk/COVID-19-research/approved-COVID-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvalsamendments/managing-your-approval/.

Ethical review of research sites

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/qualityassurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improvingresearch/learning/

With the Committee’s best wishes for the success of this project.

Yours sincerely

Email: gmwest.rec@hra.nhs.uk

11 Table of extracted data for systematic review example

Extracted data example for publication				
Author, year	Purpose	Participants	Methodology, data collection and analysis	Key findings
Kadushin and Kulys 1994	To assess how involved patients and families are in the discharge planning process	80 Social Care Professionals	Interviews	Patient safety key factor in discharge planning for social workers and physical needs of care. Goals around discharge most often set by social worker, not by the patient and not if they have cognitive impairment
Jamieson *et al.*, 2016	This study aimed to describe the experience of carers when a patient with dementia transitions home from hospital.	46 carers	30 over the phone interviews and 2 focus groups	The transition to home is difficult due to inconsistent, and often non-existent, discharge planning, resulting in no or delayed access to services.
Kaiser and Kaiser 2017	Case study of the experience of carers' experience during hospitalisation of relative with cognitive impairment	Case study	Case study	The discharge process was rushed and based on availability and not suitability. Appropriate medications were not provided at discharge, the family was not communicated with at discharge, regarding test

				results and the patient's medical condition.
Digby *et al*., 2018	The central research question of the study was "What are the factors which impact on the care of people with dementia in subacute geriatric rehabilitation hospitals?	30 participants	30 conversational interviews with patients with cognitive impairment and 120 hours of ethnographic observations	Person centered care should be used by nurses to ensure that the patient is involved in discharge decisions as patients are currently not given the opportunity to contribute to decision making.
Kaiser and Varghese, 2014	Case study focusing on the poor discharge experience of a patient with dementia	case study	case study	Multiple medication errors made on discharge due to the patient being discharged without acknowledgement of his dementia diagnosis. Healthcare professionals must include carers in discussions of medication changes before discharge as rushed discharges can lead to medication errors for patients with dementia.

Shyu, 2009	To explore the changing needs of family carers of discharged elderly persons during the transition from hospital to home.	16 carers	Interviewed before hospital discharge, two weeks after discharge and one-month post discharge	Family carers reported various discharge needs, including information on the care receiver's condition, symptom monitoring and management, personal care delivery, emergency management, help in mastering personal care skills, handling the care receiver's emotions, making the care receiver compliant, and setting up continuing services, and emotional and manpower support. The needs of family carers during the discharge transition changed over time.
Mockford *et al*, 2015	To explore the experiences of carers and people living with memory loss of hospital discharge	15 carers, 15 patients and 17 health care professionals	15 Interviews with patients/carers. 7 carer diaries. 17 staff interviews. 5 carers attended a focus group.	Requirement for a mutually agreed and meaningful discharge plan a named coordinator point of contact for services and further support needed for carers and patients. Carers and patients are often excluded from the discharge process.

Huby *et al*., 2004	The research aimed to address the lack of understanding of the impact of organizational context on discharge planning and the way this frames opportunities for patients' participation in decision-making.	22 patients. Unspecified number of health and social care professionals	22 patients interviewed in hospital and 11 interviewed post discharge. Health and social care professionals also interviewed. 2 case studies explored in depth	Findings suggested that risk management was a central driver of the discharge planning process, and that risk management and patients' participation were linked in complex ways.
Fitzgerald *et al*., 2011	To understand the family carers' experience of hospital discharge planning and how well the discharge plan, for patients with dementia, meets the needs of the family carer	25 carers	Semi structured interviews with carers	Adhoc and insufficient communication from staff to carer concerning the hospital discharge process. Family carers did not see themselves as involved in the discharge process. Discharge decisions made by health and social care staff.
Cooper and Deeks, 2012	To identify good practice and gaps in hospital admission and discharge medication processes, for patients living with dementia	20 health care professionals from primary and secondary care	Interviews	Identified ineffective communication an issue during discharge, underdeveloped planning processes and no standardised system to identify patients with dementia. Good practice based on

				individual champions and specific good communication practices. Requirement for effective communication and systems between patients, carers, hospital staff and primary care. Further training needed for health care staff around the patient journey.
Gupta *et al*., 2006	To audit a relatives communication clinic during the hospital discharge process	47 Families	Audit	Feedback showed that the multidisciplinary team and trainee health-care professionals benefited from the clinics: for example, it reduced fragmented care plans, helped timely discharge planning and empowered junior staff.
Norman, 2003	To explore the ways in which people with dementia are cared for when admitted to hospital for acute care.	4 focus groups with health professionals (n=26). 8 participants recruited for ward observation. Semi structured	Focus groups, ward observation, semi-structured interviews	The patient with dementia can be reduced to their medical needs during the hospital discharge process, their holistic requirements are not considered.

		post discharge interviews with 4 patients and 3 family members		Relative and/or carer involvement in the discharge process substituted for patient involvement. Considerations of risk undermine patient involvement in hospital discharge decision making.
Telford, 2015	Aim to explore the experiences of people with dementia when they are hospitalized for physical health conditions	8 carers	Interviews	Patients with cognitive impairment were excluded from the hospital discharge decision making process with health and social care professionals often making decisions in isolation. The day of discharge was experienced as unorganized with transport delays having a negative impact on the patient with dementia.
Rhynas *et al.*, 2018	To gain an in-depth understanding of the decision-making processes involved in the discharge of older people	6 patients with cognitive impairment	Narrative case studies were created and were thematically analysed	Patient with cognitive impairment excluded from hospital discharge decision making and felt unable to change decisions made on their

	admitted to hospital from home and discharged to a care home,			behalf. The opinions of family members and carers regarding discharge destination are privileged above patient views. Patients are often objectified in hospital discharge decision making by considerations of risk.
Kuluski *et al*., 2017	To understand the hospital experience of carers patients with alternate levels of care and cognitive impairment who were waiting for long-term care from the hospital	15 carers	12 semi-structured interviews	Hospital pressures to free up bed space leaves patients vulnerable to being discharged before appropriate community resources are identified. Patients reduced to medical needs.
Macmillan, 2016;	To explore the impact of hospital discharge on the wider wellbeing of older people	2 carers for patients with dementia.	Unclear	Patients often discharged without appropriate safeguarding and discharged home without care packages in place.
Bauer *et al*, 2011b	To explore family carers' perceptions of hospital discharge planning and preparation	25 Family carers	Interviews	Discharge planning often adhoc with no formal discharge plan available.

Deeks *et al*, 2016	To explore medication processes in acute care episodes and care transitions for patients with dementia	51 health and social care professionals and carers	Semi structured interviews	Medication management during hospital discharge, for patients with dementia, is suboptimal. Errors in prescribing and administration during discharge present a safeguarding risk. The Lack of an ongoing systematic approach to the medication communication discharge process, presents a governance issue leaving patients at risk.
Redwood *et al*, 2016	To find out what 'home' means to older people and people with memory loss in relation to their sense of identity.	60 participants with dementia and their carers	Interviews	Considerations of risk exclude patients living with dementia from discharge destination decision making. Risk assessment must be balanced with patient desire to be discharged home and professional opinion must not be prioritized. Discharge must not be rushed.

Parliamentary Health Service Ombudsman, 2016	A report of investigations into unsafe discharge from hospital	4 case studies into discharge for patient living with dementia	Complaints	Patients living with dementia are being discharged before they are ready to leave hospital. Patients are not being assessed or consulted appropriately before discharge and are being discharged without discharge care plans, there is a lack of co-ordination in and between health and social care services. Patients are being discharged without proper capacity assessments. There is a lack of safeguarding during the discharge process and discharge is sometimes occurring at night.

Poole *et al*, 2014	How assessments of residence capacity are performed on general hospital wards for patients potentially lacking capacity	35 interviews with health and social care professionals. Twenty-nine patient interviews and 28 interviews with a nominated relative. Ethnographic sessions- 111 days of ward-based field data were collected regarding 29 patient cases. Three focus groups of health and social care professionals (n = 22) and one group of three carers plus two voluntary agency staff members.	Interviews, ethnographies and focus groups.	Patients living with dementia undermined by relatives and health care professionals from taking part in decisions regarding discharge destination due to capacity assessments. Formal assessment outcomes and opinions of professionals privileged above patient opinion.
Kable *et al*., 2015	To report health professionals' perspectives on the discharge process for people with dementia and their carers	33 health and social care professionals	4 focus groups	Poor discharge planning evident for patients living with dementia. Pressure to discharge patients before appropriate due to hospital pressures. Lack of community resources available at discharge. Lack

				of safeguarding in relation to medication management at discharge.
Boaden, 2016	Report into dementia care in hospitals in the UK	FOI request to all trusts and survey of 570 people affected by dementia	Case studies of patients living with dementia during hospital discharge process	Identified often no formal discharge plan available. Discharges at night and rushed discharges common.
Cumbler *et al*; 2008	Case study of patient living with dementia including an analysis of the barriers to successful transition	One patient	Case study	Lack of safeguarding in relation to medication during discharge process. Discharge occurring over the weekend inappropriately
Bauer *et al*, 2011a	To explore whether hospital discharge practices meet the needs of the family carer of a person with dementia.	25 Family carers	Interviews	Adhoc discharge planning and no formalized discharge planning process evident for patients living with dementia
Coleman and Roman, 2015	To explore facilitators and challenges family carers face in assuming post discharge family caregiving roles and completing complex care tasks	32 family carers	Focus groups	Family carers may have different goals to patients living with dementia which may impact on the experience of discharge for the patient.

Dyrstad *et al*., 2015	To explore older patients' participation during hospital admission and discharge.	41 older patients and relatives	Observations and conversations	Patients excluded from discharge discussions and decision making which took place amongst health care professionals. Patients often discharged inappropriately or too quickly due to hospital pressures and ward routine. Relatives can function as advocates during hospital discharge. Health care professionals can involve patients living with dementia to be involved in discharge decision making. Patients often reduced to medical needs.
Gilmore- Byovski, 2017	To describe skilled nursing facility (SNF) nurses' perspectives on the experiences and needs of persons with dementia (PwD) during hospital-to-SNF transitions	40 nurses	Interviews and focus groups	Patients living with dementia often excluded from the discharge decision making process. Requirement for bed space privileged above patient discharge needs. Organizational needs of hospital placed above

				patient welfare leading to unsafe discharge. Poor discharge planning evident.
Emmett *et al*, 2014	To examine safeguarding role of relatives during hospital stay of patient living with dementia	35 interviews with health and social care professionals. Twenty-nine patient interviews and 28 interviews with a nominated relative. Ethnographic sessions- 111 days of ward-based field data were collected regarding 29 patient cases. Three focus groups of health and social care professionals (n = 22) and one group of three carers plus two voluntary agency staff members.	Interviews, ethnographies and focus groups.	Patients living with dementia often replaced by relatives during discharge planning. Ideas around risk and safety lead to exclusion of patient living with dementia from discharge decision making. Deficiency is community services impacting on hospital discharge process.

12 Extraction example for systematic review

Heading	Detail	A Relative Safeguard? The Informal Roles that Families and Carers Play when Patients with Dementia are Discharged from Hospital into Care in England and Wales
Bibliographic details		Charlotte Emmett,*,† Marie Poole,** John Bond,** and Julian C. Hughes*** 2014
		International Journal of Law, Policy and The Family
Name of Reviewer		LP
Eligible	Does the evidence fit within the scope of the review? Is it quantitative only? Or professional data only?	Qual
Reviewer rating	Matrix	
Typology	A systematic or literature review? Case study? Primary research? Descriptive?	Primary research. Over a period of 9 months between June 2008 and June 2009 (including a 3-month analysis period at 6 months), 111 days of ward-based field data were collected. Fieldwork was undertaken on three general elderly care wards, in two hospitals within two NHS healthcare trusts in the north-east of England. Fieldwork centred on the care and discharge process of 29 patient cases. In total, 92 formalized qualitative in-depth interviews were conducted with all stakeholders. The 35 interviews with health and social care professionals represent perspectives from a broad range of disciplines and include: senior and junior doctors (physicians and psychiatrists); nursing staff (qualified and non-qualified, senior and junior, and psychiatry liaison); social workers; occupational therapists, a physiotherapist, and an IMCA. Twenty-nine patient interviews and 28 interviews with a nominated relative were conducted at the

		point of discharge and at 3 months post discharge where possible.
Participants	Evidence from service users, carers, policy or practice?	A series of focus groups were conducted between April and May 2009 to incorporate a broader range of views, values and experiences. Participants were asked to suggest if and how residential capacity and best-interest decisions could be improved through discussing hypothetical vignettes derived from the ward-based data. Three groups of health and social care professionals (n ¼ 22) and one group of three carers plus two voluntary agency staff members participated. Professional participants were represented by: general practitioners (including a trainee); social workers; occupational therapists; nurses (including a nursing home placement assessor); psychologists, a chaplain; and a care home manager
Study aims	What were the aims and purpose?	It is from this premise that we set out to explore, through our data, the informal role of relatives during the discharge-planning process and the extent to which they do, in fact, fulfil an effective safeguarding role when decisions are made to discharge older patients with dementia from hospital either back home or into long-term care. It is through this enquiry that we hope to develop a clearer picture of how the MCA is being implemented in practice and the extent to which the current statutory framework of the MCA is effective in safeguarding the rights of incapacitated older people.

Key findings	What are the key findings of the study?	Themes have been grouped under three headings, namely: the different informal roles that relatives play during discharge from hospital (including the assumption of a caretaking or safeguarding role); the potential barriers that may prevent relatives from carrying out an effective safeguarding role during discharge planning; and those positive factors which helped relatives to safeguard the interests of dementia patients during discharge.
Evaluative summary	Draw together brief comments on the study as a whole and its strengths and weaknesses. Is further work required? What are its implications for policy, practice and theory, if any?	Broad range of methods with professionals, carers and patients.
Service users' and carers' perspective	Does the study report on the experience of service users? Does the study report on the experience of carers? How were they involved in the study (e.g. as advisors for the research, in the design and execution of the study, in dissemination)?	See above
Ethical Approval	Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately? Has confidentiality been maintained	Ethics apparent

Aims	Are the aims and purpose of the study clearly stated?	Clear above
Setting	What is the geographical and care setting for the study?	see above
Rationale	What is the rationale and appropriateness for this choice?	
Detail	Is there sufficient detail about the setting?	
Timing	Over what period did the data collection take place?	see above
Sample	Inclusion criteria	Mixed criteria
	Exclusion criteria	
Selection	How was the sample selected? Were there factors that influenced how the sample was selected? ACCESS/TIMESCALES ETC	Not clear re focus groups Participating wards were selected based on specialism and case-mix (care of the elderly and ortho-geriatric care, including acute and rehabilitation settings). The broad inclusion criteria adopted in the study reflected the naturalistic approach to enquiry and the underpinning patient-centred ethos of gaining perspectives of patients with dementia regardless of advancement of the condition. Therefore, both patients who were able and unable to consent to participation were included. Personal and nominated consultee agreement was obtained for those patients whom the researcher considered unable to provide written consent. A member of the clinical team made the initial approach to the patients, which the researcher then followed up. Contact with relatives was established through the patients. Cases were then theoretically sampled (Silverman, 2005) to ensure participants represented a broad range of characteristics including: reason for admission; living

		arrangements; formal and informal support networks; capacity decision and discharge outcome. The sample also extended to represent key events and interactions which characterized cases such as discharge planning meetings; home visits and input from psychiatry services. Ward staff consented to be observed, and professionals were purposively sampled for an additional qualitative interview
size	What was the size of the sample and groups within the sample?	see above
Appropriateness	Is the sample appropriate in terms of its ability to meet the aims of the study? The depth and breadth of data collected?	Breadth
Data collection	Methods: what data collection methods were used? Was the data collection adequately described and rigorously conducted?	See above variable, topic guides for interviews discussed alongside the ethnographic process
Role of researcher	What is the role of the researcher? Are there any conflicts of interest potentially?	Not clear but clinical team recruitment
Fieldwork	Is the process of the fieldwork adequately described?	yes
Data analysis	How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis (e.g. use the	Analysis of coded transcripts was conducted through a series of data workshops (MP, JB, and JCH). This facilitated the development of a coding framework for all data, from which themes emerged. Emergent themes were further developed through the use of memos leading to key concepts in the data (Charmaz,

	original data, iterative analysis, efforts to prove validity and reliability) Is the study set in the context in terms of findings and relevant theory?	2006). Data was managed using NVIVO software (NVivo, 2010). For each of the 29 cases, the multiple sources of field data were synthesized into 'case studies' of decision-making processes relating to judgments on capacity and discharge. Using constant comparative methods (Glaser and Strauss, 1967), case studies were then analysed highlighting similarities and differences. This allowed common themes and key differences to emerge between cases, indicating examples of good practice or potential areas for improvement in the processes of assessment of residence capacity, best-interest judgments, and discharge.
Researchers potential bias	Are the researchers own positions and bias outlined? Indicate how they could affect the study in terms of analysis and interpretation of data?	no
Reflexivity	Are the findings substantiated by the data and has consideration been given to any limitations of the methods that may have affected results?	Extensive detail and quotations
Outcomes	What outcome measures were adopted? What was the impact of the study for service users? Carers? Practicioners? Organizations responsible for services?	

Findings	Themes	Frequently relatives took on informal roles assisting older patients with daily living, facilitating communication between the patient and health and social care staff, which enhanced an older person's welfare and decisional abilities on hospital wards (Boyle, 2013). Relatives acted as advocates for patients who were too ill or confused to articulate their own views and wishes: INT:…my wife's done most of the talking you see 'cos I've been in hospital. She's done most of the talking. (Interview: 021208, lines 142–143: Patient (Mr Coleman)). During their interactions with health and social care professionals, relatives also acted as information gatherers, questioners, observers, and prompters. However, not all relatives we observed were proactive information-gathers, often reluctant to interfere with hospital protocols or to question professional views (Efraimsson et al., 2006). Also, while the IMCA had a statutory right of access to a patient's medical and social care records, which provided her with important background clinical and social information concerning the patient, relatives often found it difficult to access clinical information in hospitals. This may have been due to issues surrounding patient confidentiality, poor communication by professionals or relatives simply not knowing where to access the required information. A. Lack of Information and 'Signposting' by Professionals Although we observed that decisions about discharge were made in other contexts (such as ward rounds, informal meetings between staff, patients, and relatives), we found that discharge planning meetings (otherwise known as case conferences) often provided the formal venue for best-interests decision-

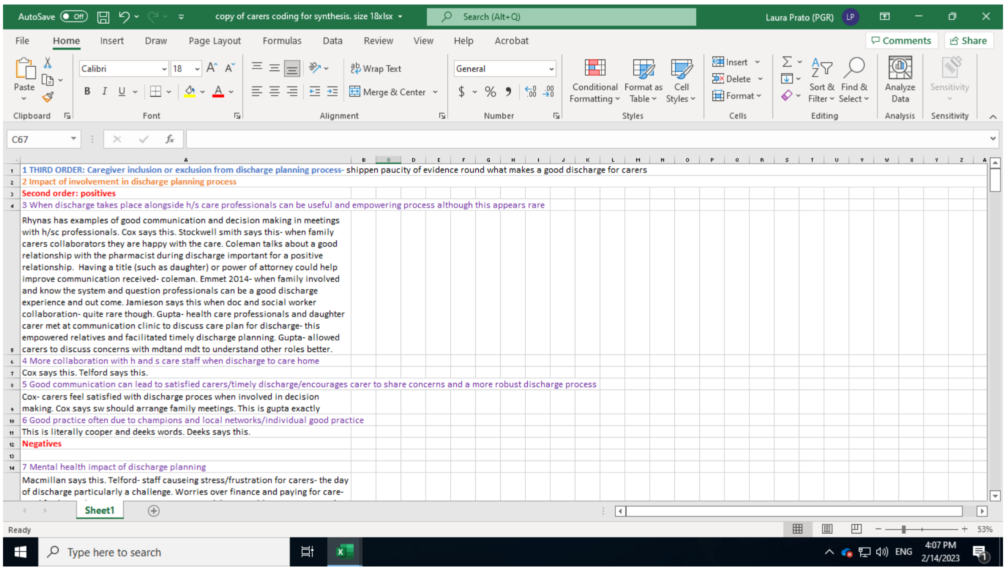
		making prior to discharge. However, relatives were not always aware of the purpose of those discharge planning meetings, which were not always properly signposted by professionals as being relevant to discharge placement. Several relatives also expressed concerns that they had not been given enough timely information by professionals to be fully informed and prepared for discharge planning meetings. As such, they felt that they were not adequately prepared to make informed judgments about where patients should live on discharge, or to challenge professional views when they felt this was necessary. The ability of relatives to represent and safeguard a patient's best interests was also called into question when conflicts of interests arose between relatives and patients. In the extract below, one junior doctor alludes to the difficulties faced by Mrs Salter's daughter who had to uncouple her own interests (that her mother's home, which she saw as her inheritance, was to be used to pay for a private care home placement) from the best interests of the patient. C. Inequalities of Power Older or less assertive relatives found it difficult for their voices to be heard in the discharge-planning process or to influence and challenge discharge outcomes, even when they thought this was necessary. Inequalities of power in the decision-making process were occasionally the result of a relative's perceived deference to professional opinion or hospital procedures, or the desire to conform to the views of stronger willed, more coercive family members. The result was that many relatives appeared to be ill-equipped to safeguard patients' best interests. This extract suggests how easy it can be for decisions to

		become ‘medicalized’ by professionals when they are privy to clinical information that relatives are not party to, with the result that relatives can suddenly become excluded from the decision-making process- see quote for professional making the decison over relative. ‘you can’t look after him’, ‘pardon’, ‘you can’t look after him,’ I said ‘but why?’ ‘well you know he’s got short term [memory loss],’ I says, ‘well I know that’ [mmh mmh] ‘I know but he’s got to be turned over three times through the night’, ‘what’, ‘he can’t turn himself over’. So straight out of my hands then.' Relatives also struggled to carry out effective safeguarding roles at a time when they were often coming to terms with the emotional stress and burdens associated with their close relative or spouse being suddenly admitted to hospital, and the potential impact that any discharge decision would have on their own lives.
	Conclusions	Frequently, decisions about changes of accommodation will be made suddenly in an older person’s life, during ‘the crisis of hospitalisation’ (McAuley et al., 1997) and often when a patient’s cognitive abilities and health are fluctuating. Professionals have the difficult job of weighing and ranking complex clinical needs alongside competing personal, social, and ethical factors, where issues of risks (to the patient and to others) will often weigh heavily in any placement decision made (Emmett et al., 2013; Greener et al., 2012). Family and close friends – most often the primary carers in older patients’ lives – may wish to assert their own personal agendas, so that conflicts of interest can arise between patients and their carers (Brindle and Holmes, 2005). Typically, older people with

		dementia fade into the background during this decision-making process, while others decide on their relocation into permanent care (Dwyer, 2005). Moreover, decisions about hospital discharge and living arrangements are inextricably linked with diminishing community services and finite hospital resources, where ‘effective bed management’ and ‘improving patient throughput’ have become common bywords in hospital discharge planning (Banerjee et al., 2008). This can lead to ill-conceived capacity assessments being carried out by professionals on busy hospital wards and best-interests decisions that fail to comply with the legal standards of the MCA (Emmett et al., 2013).
opinions	What is argued?	see above
Policy and practice	Generalizability: To what extent are findings generalisable? What is the country of study? How applicable are the findings to the UK system? Are the conclusions justified?	UK
Implications for policy	What are the implications for policy?	see above
Implications for practice	What are the implications for practice?	see above
Other comments	Format	
Links to references to follow up		
Decisions	second reviewer name	
agreement with reviewer		yes
Inclusion	Should this be included?	
Topic question	date	4/8/2019

Date	casp	yes

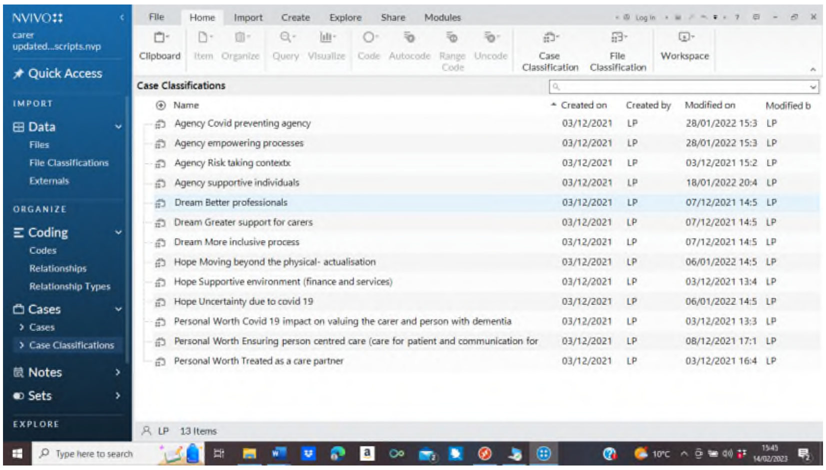
13 Example systematic review synthesis



	A
1	1 THIRD ORDER: Caregiver inclusion or exclusion from discharge planning process- shippen paucity of evidence round what makes a good discharge for carers
2	2 Impact of involvement in discharge planning process
3	Second order: positives
4	3 When discharge takes place alongside h/s care professionals can be useful and empowering process although this appears rare
5	Rhynas has examples of good communication and decision making in meetings with h/sc professionals. Cox says this. Stockwell smith says this- when family carers collaborators they are happy with the care. Coleman talks about a good relationship with the pharmacist during discharge important for a positive relationship. Having a title (such as daughter) or power of attorney could help improve communication received- coleman. Emmet 2014- when family involved and know the system and question professionals can be a good discharge experience and out come. Jamieson says this when doc and social worker collaboration- quite rare though. Gupta- health care professionals and daughter carer met at communication clinic to discuss care plan for discharge- this empowered relatives and facilitated timely discharge planning. Gupta- allowed carers to discuss concerns with mdtand mdt to understand other roles better.
6	4 More collaboration with h and s care staff when discharge to care home
7	Cox says this. Telford says this.
8	5 Good communication can lead to satisfied carers/timely discharge/encourages carer to share concerns and a more robust discharge process
9	Cox- carers feel satisfied with discharge proces when involved in decision making. Cox says sw should arrange family meetings. This is gupta exactly
10	6 Good practice often due to champions and local networks/individual good practice
11	This is literally cooper and deeks words. Deeks says this.
12	Negatives
13	
14	7 Mental health impact of discharge planning
	Macmillan says this. Telford- staff causeing stress/frustration for carers- the day of discharge particularly a challenge. Worries over finance and paying for care-

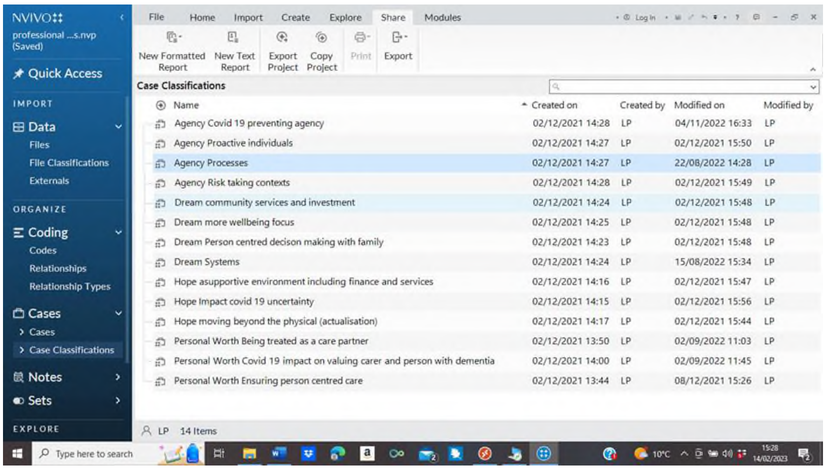
14 NVIVO coding example

Professional and Carer transcript coding



Case Classifications

Name	Created on	Created by	Modified on	Modified b
Agency Covid preventing agency	03/12/2021	LP	28/01/2022 15:3	LP
Agency empowering processes	03/12/2021	LP	28/01/2022 15:3	LP
Agency Risk taking contextx	03/12/2021	LP	03/12/2021 15:2	LP
Agency supportive individuals	03/12/2021	LP	18/01/2022 20:4	LP
Dream Better professionals	03/12/2021	LP	07/12/2021 14:5	LP
Dream Greater support for carers	03/12/2021	LP	07/12/2021 14:5	LP
Dream More inclusive process	03/12/2021	LP	07/12/2021 14:5	LP
Hope Moving beyond the physical- actualisation	03/12/2021	LP	06/01/2022 14:5	LP
Hope Supportive environment (finance and services)	03/12/2021	LP	03/12/2021 13:4	LP
Hope Uncertainty due to covid 19	03/12/2021	LP	06/01/2022 14:5	LP
Personal Worth Covid 19 impact on valuing the carer and person with dementia	03/12/2021	LP	03/12/2021 13:3	LP
Personal Worth Ensuring person centred care (care for patient and communication for	03/12/2021	LP	08/12/2021 17:1	LP
Personal Worth Treated as a care partner	03/12/2021	LP	03/12/2021 16:4	LP



Case Classifications

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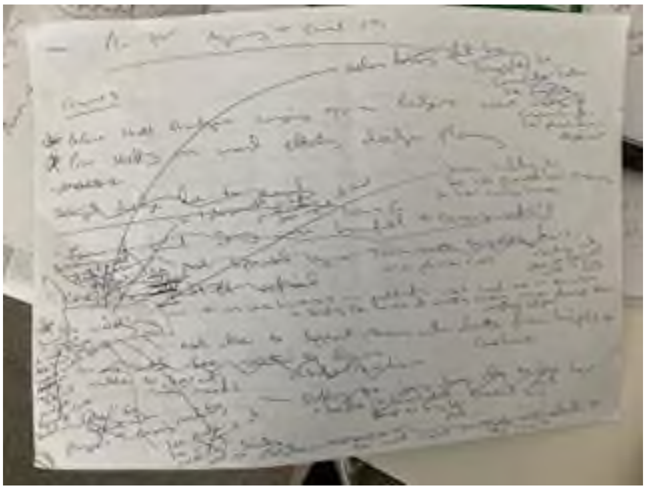
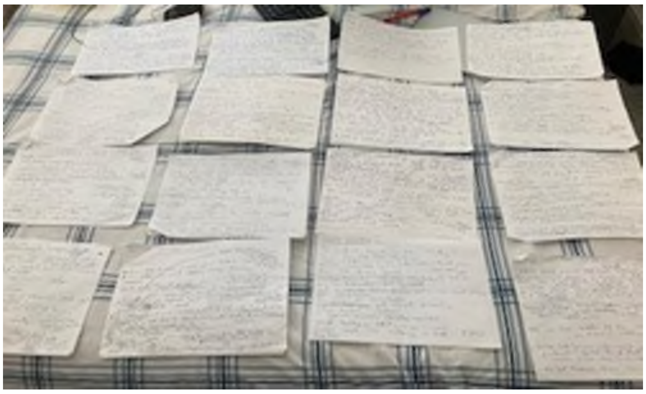
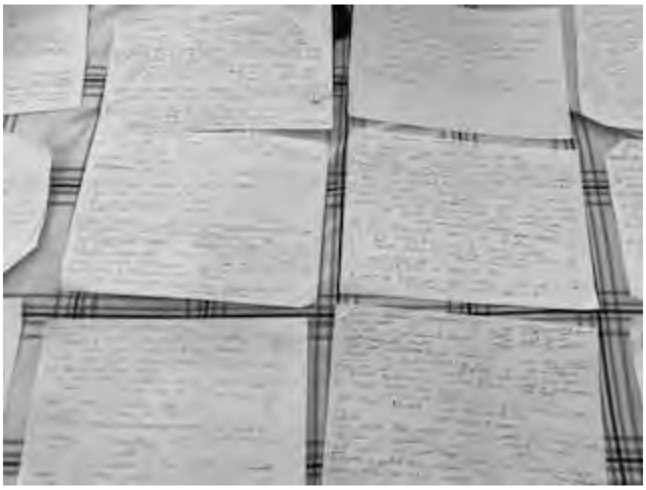
Agency Covid 19 preventing agency	02/12/2021 14:28	LP	04/11/2022 16:33	LP
Agency Proactive individuals	02/12/2021 14:27	LP	02/12/2021 15:50	LP
Agency Processes	02/12/2021 14:27	LP	22/08/2022 14:28	LP
Agency Risk taking contexts	02/12/2021 14:28	LP	02/12/2021 15:49	LP
Dream community services and investment	02/12/2021 14:24	LP	02/12/2021 15:48	LP
Dream more wellbeing focus	02/12/2021 14:25	LP	02/12/2021 15:48	LP
Dream Person centred decison making with family	02/12/2021 14:23	LP	02/12/2021 15:48	LP
Dream Systems	02/12/2021 14:24	LP	15/08/2022 15:34	LP
Hope asupportive environment including finance and services	02/12/2021 14:16	LP	02/12/2021 15:47	LP
Hope Impact covid 19 uncertainty	02/12/2021 14:15	LP	02/12/2021 15:56	LP
Hope moving beyond the physical (actualisation)	02/12/2021 14:17	LP	02/12/2021 15:44	LP
Personal Worth Being treated as a care partner	02/12/2021 13:50	LP	02/09/2022 11:03	LP
Personal Worth Covid 19 impact on valuing carer and person with dementia	02/12/2021 14:00	LP	02/09/2022 11:45	LP
Personal Worth Ensuring person centred care	02/12/2021 13:44	LP	08/12/2021 15:26	LP

15 Examples of hand coding







16 Plan for systematic review

Background

The World Alzheimer's Report (2016) called for the opinions of those with dementia and their carers to be more integrated into research around care models and decisions in relation to the commissioning of services. The report (World Alzheimer's Report, 2016) identified that the role of the professional dementia specialist will become vital in the coming decades as the prevalence of dementia rises (World Health Organisation, 2015) and more general health professionals will need to develop their knowledge and skillset. According to Alzheimer's Society (2014) 7% of population over 65 have dementia, over 1 million people by 2025. It has been acknowledged that more information on carer and patient experiences of dementia and specialist dementia nursing services which can be hospital or community based. To consider the acceptability to carers for adults with a dementia diagnosis of the acceptability of community-based specialist nursing services. Alzheimer's Research UK (2015) says impact on carers is immense and need further research on interventions to help carers cope with caring for loved ones in the community. The challenges faced by carers are varied and include emotional strain as well as managing the practicalities of caring for adults with dementia (Feast *et al.*, 2016). Research has suggested that partnership working (Bunn *et al.*, 2017) facilitated by specialist teams in the community could lead to improvements in carer satisfaction and the quality of services available for community dwelling patients with dementia and their carers. Some research (Moniz-Cook *et al.*, 2008) has suggested that a community-based nurse with specialist knowledge of dementia care can have a positive impact on carer experiences. Other research (Robinson *et al.*, 2010) has suggested that increasing skill mix in community primary care teams to include specialist nurses would result in more holistic care models and practices. It has been recognised that further development of the community dementia specialist nurse role is required to ensure the success of the post (Page and Hope, 2013). A systematic review (Bunn *et al.*, 2016) was carried out in 2012 to assess the effectiveness and scope of admiral nurses which found that all community support for carers of older people with dementia was valued by those carers. This systematic review will differ from and build upon the 2012 review, as it will broaden the scope from just admiral nurses and the focus will be upon the experience of carers, rather than the potential effectiveness of services. The authors verified that no other systematic review into this topic area is currently registered on the PROSPERO (University of York Centre for Reviews and Dissemination, 2017) website.

Aims/objectives.

The aim of this review is to synthesise the opinions and experiences of carers and individuals with a dementia diagnosis of community-based specialist dementia nursing services. Researchers aim to identify the acceptability of community-based specialist dementia nursing services for carers and adults with a dementia diagnosis and identify the positive or negative experiences of receiving support from specialised nursing teams.

The review question.

What are the experiences and opinions of carers and individuals with a dementia diagnosis living at home of community-based specialist dementia nursing services?

Search Strategy Methods

The **SPIDER** (Alison *et al.*, 2012) method was used to devise an appropriate question. I will use, truncation, Boolean operators, nesting and use the filters available in each different type of search engine (Booth, 2016). I will identify all synonyms and consult the MESH terms (US National Library of Medicine, 2017) to identify all possible search words. Details of the search strategy development will be documented. The search strategy question designed for use in searching the electronic data bases is detailed below:

Sample: Carer* OR Family* OR Relative* OR patient* OR dementia diagnosis

Phenomena of Interest: Community Specialist dementia nurs* OR Community Dementia nurs* OR specialist dementia servic*

Design: Interview* OR Focus group* OR Survey* OR Questionnaire* OR Ethnography*

Evaluation: View* OR Experience* OR Perspective* OR Attitude* OR Opinion* OR Belief* OR Thought*

Research type: Qualitative

Electronic databases: Proquest Social Sciences Premium Collection; Scopus; Web of science; MEDLINE; CINAHL; EMBASE; PsychInfo

Researcher will also us ‘snowball’ searching to identify grey literature and liaise with supervisors to identify further literature. Journal article reference lists will be hand searched to prevent any literature being overlooked in this process. I will also search Google Scholar.

Inclusion criteria

1 Studies must be in in English. This is for practical reasons as researchers do not have access to translators.

2 Qualitative methodology can include: focus groups; interviews, surveys, ethnographies

3 Must have been published between 1990 and 2017 to ensure that results are relevant to modern evidence-based era of health care research

4 Studies must be based in the community and individuals with dementia must be living at home

Exclusion criteria

1 Quantitative methodology research studies such as: randomised controlled trials; cohort studies and before and after studies

2 Studies published in languages other than English.

3 Studies based in the hospital setting or nursing home.

Search strategy / study selection.

All results from the data base searches will be entered into endnote X7 where one researcher will review all titles and abstracts against the inclusion and exclusion criteria. 20% of the returned results shall be reviewed by a second researcher to ensure the reliability of the primary researcher sifting. If there is no consensus, the primary researcher will re-examine the titles and abstracts and review with the second researcher. The two researchers shall review all included studies once available. A third researcher shall be involved if consensus cannot be reached by the first and second reviewer. Results shall be grouped into included and excluded and the physical copies ordered through the library or downloaded online.

Data extraction

Once paper copies of the studies included have been obtained, data will be extracted by one researcher using a data extraction form developed in accordance with guidance in Noyes and Lewin (2011) and Munro *et al.* (2007). Data to be extracted will include: country, title, authors, aims of study, ethical approval and considerations, study setting, theoretical background of study, sampling approach, participant characteristics, data collection methods, data analysis, key themes identified, recommendations made by authors and authors assessment of study quality, including identified limitations (Munro *et al.*, 2007). 20% of the data extraction forms will be assessed by a second researcher to ensure quality control. The researcher will repeat the process if the forms are judged to be unacceptable by the second researcher. A table shall be created detailing the specifics of each study.

Quality assessment- risk of bias

The CASP tool for qualitative research (Critical Appraisal Skills Programme, 2017) will be used to assess the risk of bias in each of the studies and to ensure that transparency of method is evident in each of the studies to be included. One researcher will complete the quality assessment process and another researcher will review 20% of the completed CASP tools to ensure the reliability and validity of all included studies. A section of the output to be disseminated will explore the risk of bias identified in the studies through the use of the CASP tool for qualitative research. A table shall also be included in the final output detailing author bias risk findings.

Coding and Synthesis Analysis of subgroups or subsets

Researchers will use meta-ethnography (Britten *et al.*, 2002) to identify and synthesis the experiences and opinions identified in the literature. The key researcher shall read through each of the studies multiple times. The researcher will analyse the identified literature using the procedure outlined in Noblit and Hare (1988) by identifying reoccurring concepts and metaphors across the studies. These concepts shall be entered into a table to illuminate the studies relationships to each other. The studies shall then be translated into one another if possible to further illustrate key concepts.

Interpretations shall be developed arising from the concepts identified (Britten *et al.*, 2002) and researchers will utilise published guidance in the development of a meta-ethnography (Lee *et al.*, 2015). Researchers will develop separate subgroup synthesis for carers and individuals with a dementia diagnosis to illuminate the findings for each subgroup. The author believes that Meta-ethnography will be the most appropriate method for analysis and synthesis as the method of comparing and translating studies ensures that findings are emerging across the studies and allows for a true synthesis of findings (Britten *et al.*, 2002). The authors supervisor shall review the tables emerging from the analysis and the subsequent synthesis and comment on the validity of the final output. Any disagreements between the author and the supervisor shall be resolved with reference to a third researcher.

Dissemination plan

Results shall be disseminated through publication in a relevant journal and attendance at an international conference. Potential audiences include: medical professionals; community health care commissioners; stakeholders including carers and individuals with dementia; health care researchers and charities. Researchers believe that the findings will have international significance to policy as they will not be confined to the UK setting only.

People and roles

The author shall conduct the search strategy, data extraction, quality assessment and synthesis with the author's supervisor assisting with the 20% quality assessment, data extraction and sifting being completed by the author's supervisor to ensure that the authors work is accurate.

Timetable

November: Devise search strategy in consultation with specialist librarian

December: Conduct searches of specialist electronic databases. Search strategy to be adjusted if results unmanageable. All results to be entered into Endnote X7 for sifting to begin.

January- March: Sifting to occur. Supervisor to check agreement on 20% of results. Once completed, all included results to be acquired via library if necessary.

April- June: Data extraction and quality assessment to be completed. Supervisor to check 20% of extracted forms and completed CASP tools.

July: First draft of meta-ethnography to be completed.

August: Final draft of meta-ethnography to be completed and publication output to be in draft stage.

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17 Systematic review protocol

Primary question

What are the experiences of patients living with dementia and their familial carers, during the hospital discharge planning process?

Secondary question

What are the key factors that should guide health care professionals in safeguarding the wellbeing of patients and carers of adults living with dementia, during the discharge planning process from hospital?

Aim

To identify and synthesise available evidence, in regards to the experiences of patients living with dementia and their familial carers, during the hospital discharge planning process.

Objectives

- To identity the key factors that impact on the discharge from hospital process experience, for patients and carers of adults living with dementia, through the completion of a systematic review
- To identity any omissions in the evidence base, regarding the experience of patients living with dementia and their carers during the hospital discharge process
- To identify the principles that should guide health care professionals, in their support of physical, emotional and social wellbeing during the hospital discharge process, for adults living with dementia and their carers

Method

Systematic Review

Searches

Search strategies:

Both published and unpublished or grey literature will be included in the systematic review. The following sources will be searched to identify published literature:

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present Embase (Ovid)
CINAHL (EBSCO)
PsycINFO
Scopus
SCIE: Social Care Online
Pubmed
Proquest
Cochrane
Web of Science

The SPIDER framework has been used to develop the search strategy.

Spider framework	
Sample	**Patients, health and social care professionals and carers of adults with cognitive impairment**
Phenomena of Interest	**Discharge from hospital process for patients and carers/relatives**
Design	**Questionnaire, survey, interviews, focus groups, case studies, ethnographies, observational studies, reviews,**
Evaluation	**Experiences**
Research Type	**Qualitative, mixed methods**

Table 2 Inclusion and Exclusion Criteria beyond spider framework

	Inclusion Criteria	**Exclusion Criteria**
Publication	**Peer reviewed journal research, reports, audits, conference proceedings, unpublished thesis, reviews, systematic reviews**	**Opinion pieces, editorials**

Language	**English language**	**Any other language**

The search terms include:

Sample (patient)	Sample (carer)	Sample (Dementia)	(Phenomena of Interest) Discharge from hospital	Evaluation (Experiences)	Design
Adult	Family	Dementia*	Return home process	Perception	Qualitative
In-patient	Relative	Cognitive Impairment	Leaving hospital	Perspective	Mixed methods
Patient	Care*	Confusion	Discharge planning	View	Realist
	Family Caregive*	Alzheimer's		Need	
	Family care*	Frontal temporal lobe dementia		Experience	
	Informal care*			Insight	
	Care-give*			Opinion	
	Spouse/wife/husband				
	Child/daughter/son/grandchild				

The following sources will be used to identify published literature:

- Electronic databases of peer-reviewed journal articles, including those covering biomedicine, nursing and allied health professions and the social sciences
- Reference lists of all studies meeting the inclusion criteria

Each database will be searched by LP, in conjunction with a librarian. Each column in the search terms table, contains synonyms for the key search terms. Each term in the column will be entered into the database and truncated where appropriate. All individual searches for each column will be combined using the "OR" Boolean operator. The 'AND' function will then be used to combine the terms to create a list of references, which will be saved into Endnote, and screened for duplicates. Records of all searches from the databases will be maintained.

Language

Must have an English language title and abstract

Date Range

All studies from 1990. The principles and understanding of care for adults living with dementia, have changed dramatically since 1990, following the seminal work of Tom Kitwood. Studies after 1990 will reflect current best practice, for the care of adults living with dementia in hospital.

Type of study to be included

Primary research studies that are qualitative or mixed methods will be included as well as relevant reviews.

Type of study to be included

Exclusion: professional discussion, opinion pieces, randomised controlled trials with no qualitative aspect, non-research and all purely quantitative research.

Design to be included

Questionnaire, survey, interviews, focus groups, case studies, ethnographies, observational studies.

Phenomena of Interest

The discharge from hospital planning process.

Includes: all aspects of care and experiences of patients living with dementia and their carers, during the discharge process from hospital, included but not restricted to:

- Nursing care, including person-centred approaches
- Behavioural / psycho-social interventions
- Organisation of care e.g. systems and processes of care delivery
- Staff factors
- Environmental design

Exclusion: discharge from care homes/nursing home settings and discharge experiences for patients without cognitive impairment.

Comparator(s)/ control

None

Context

In-patient and out-patient wards and departments within hospitals and hospices, including (but not restricted to) acute, community hospital, rehabilitation settings and emergency departments.

Evaluation

Patient and carer experiences including:

- Staff-patient-carer communication and factors
- Involvement in discharge planning process
- Multi-disciplinary working outcomes
- Organisational factors
- Safety outcomes

Data Screening

Step 1: Titles and/or abstracts of studies, retrieved using the search strategy and those from additional sources, will be screened by two review authors and studies that do not meet the inclusion criteria shall be excluded. The second reviewer will screen 20% of the results. Decisions about inclusion and exclusion of studies, shall be decided in a series of meetings between the two reviewers.

Step 2: The full text of eligible studies will be retrieved and assessed in full. If it is unclear whether an article is suitable for inclusion, an attempt to contact the author shall be made. If a response is not forthcoming within two weeks, the article shall be discarded and the reason recorded.

The review process will use two reviewers: one research student and a supervisor.

Data Extraction

Reviewer will extract study data using a customised electronic data extraction form, tailored to the qualitative systematic review methodology. The tool will be piloted on 3 articles and will be subsequently modified as required. The data extracted will include: review authors; title and year; aim; study design; participant information (includes staff, carer or patient); inclusion and exclusion criteria; setting; design; summary of content and findings including themes; quotes; strengths and limitations; recommendations and reviewer comments.

Risk of bias (quality) assessment

Risk of bias and the methodological quality of each study will be assessed using standardised published tools. The Critical Appraisal Skills Program (CASP) tool tailored to the type of research assessed shall be used. It is hypothesised that the limited amount of research available, may entail that the quality of the studies retrieved will be restricted. Therefore, all data which illuminates the experience of patients with a dementia diagnosis and their carers, during the discharge from hospital planning process will be included.

No studies will be excluded from the review based on the quality appraisal but reference will be made to study quality, during the synthesis of findings and reporting of the review.

Strategy for data synthesis

Ethnographic synthesis will be undertaken, incorporating interpretive synthesis. Ethnographic synthesis will allow the identification of themes arising from the data and facilitate higher order abstraction and theory development. The method outlined in Noblit *et al.* (1988) and demonstrated by Campbell *et al.* (2003) and Britten *et al.* (2002) shall be utilised during this process, as outlined below.

1) Getting started
2) Deciding what is relevant to the initial interest
3) Reading the studies
4) Determining how the studies are related
5) Translating the studies into one another
6) Synthesising translations
7) Expressing the synthesis

Analysis of subgroups or subsets

None planned

Dissemination plans

Plan to publish in peer reviewed journals, create practitioner-friendly summaries and present at national conferences.

Anticipated or actual start date

December 2018

Anticipated completion date

End of October 2020

Funding source / sponsor

ESRC NINE DTP

Conflicts of interest

None

Other registration details

Country

UK

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Title: The Wellbeing of People Living with Dementia and their Carers During the Hospital Discharge Process: A Qualitative Exploration
Laura Prato
Doctor of Philosophy
Newcastle University Population Health Sciences Institute
May 2024
Word Count 86,000

Abstract

The hospital discharge process in England has been criticised by several organisations due to the perceived failure to support the physical, emotional, and social wellbeing of people living with dementia and their carers (Alzheimer's Society, 2016). Despite the prioritisation of the term 'wellbeing' in policy documentation, there is limited evidence regarding the definition of wellbeing within the hospital discharge context. Against this background, this thesis presents the findings of a social constructionist, qualitative investigation into the experiences of carers of people living with dementia and clinicians and explores how the term 'wellbeing' is understood by both groups and what factors support wellbeing throughout the process of leaving hospital.

Twenty-four semi-structured interviews with carers of people living with dementia (n=14) and clinicians (n=11) were subjected to thematic analysis (Guest, MacQueen & Namey, 2011), with codes identified from the data. Drawing on the theory of wellbeing outlined by Kitwood and Bredin (1992), an Appreciative Inquiry method (Cooperrider & Whitney, 2005) was utilised to identify changes that could support the wellbeing of carers and people living with dementia.

Carers of people living with dementia frequently felt that their own wellbeing and that of their relatives was not supported during the hospital discharge process. This was especially the case in relation to policy guidance issued during the COVID-19 pandemic. Informal carers and care professionals identified that ensuring agency, personal worth and hope was crucial to defining and ensuring the wellbeing of both carers and people living with dementia during the leaving hospital process. Expert participants identified changes to the focus of the discharge process that would allow the wellbeing of people living with dementia and their carers to be prioritised. There is an urgent requirement for a change in the discharge process leading to assessments and decisions to be reconstructed to focus primarily on wellbeing for carers and people living with dementia.

Dedication

I would like to thank my supervisors for their support throughout the research project and the many changes that took place over 6 years. Thank you to Dr Clare Abley, Professor Joy Adamson and Professor Thomas Scarf for your feedback and insights during the life of this PhD project. I would also like to thank the Economic and Social Research Council for deciding to fund this project and I would like to thank my parents for all their help and support. I don’t know that this thesis would exist without your help and the many ways in which you helped me during the pandemic and beyond. I am so grateful to my husband for listening to me talk about the research, the thesis writing process and for helping me always in ways both small and large. Thank you to my little boy Alfie who was born during the life cycle of this PhD and who always makes me smile.

I would especially like to thank the participants of this study for giving up their time during a difficult and stressful period to speak to me about their experiences. I am in awe of your strength and love.

I would like to dedicate this thesis to the victims of COVID 19 and the carers of the victims of COVID 19, many of whom were unable to say goodbye or access their loved ones during this period. I can only admire your strength.

Thank you to my examiner’s Dr Marie Poole and Professor John Keady for their insight into the thesis and its final content.

COVID 19 impact statement

I returned from maternity leave in May 2020 when my baby was 9 months old. I was 10 months into the first year of my PhD period at that point. It was a challenging process as childcare bubbles were not permitted. Further to this, my research proposal included ethnographic observations in the hospital setting and my research was in partnership with Newcastle Upon Tyne NHS Foundation Trust. I realised the research method I had chosen would not be achievable in pandemic conditions. Therefore, I was tasked with the challenge of re-writing the research proposal and rethinking my entire project, including recruitment and data collection methods. The process of adapting my research to make it compatible with pandemic conditions and to include the impact of the pandemic within the research project focus took considerable time.

I had to obtain Health Research Authority (HRA) approval, local Newcastle Upon Tyne NHS Foundation Trust Research & Development approval, NHS Research Ethics Committee (REC) approval, NIHR Portfolio access and an NHS research passport. This was due to my research being focused on the hospital context and involving interviews with health and social care professionals and carers in the community. The process of achieving these permissions was time consuming due to delays in the NHS research process caused by the pressures of the pandemic. I began applying for these permissions in August 2020 and finally received all the required permissions, including NHS Research Ethics Committee approval, in February 2021.

On top of these challenges, I had multiple 10 day + self- isolation periods due to contact with people who tested positive for COVID 19. My son also had contact with nursery staff who then tested positive for COVID 19 during January, February, and July 2021. This left my son in self-isolation for 10 days at a time and I often had to care for him, as he could not leave the house for childcare purposes. There were also multiple periods where I would be in self-isolation for up to 48 hours while waiting for the PCR test result. I estimate that I have spent over 60 days in self-isolation since September 2020. I was also restricted to one childcare bubble, in line with government guidance, for the majority of winter 2020/2021. Further to this, we contracted multiple illnesses in 2021 and 2022 owing to the easing of lockdown and the circulation of contractible illnesses.

Implementing interviews with health and social care staff during a pandemic was challenging due to the busy nature of both the NHS and social care systems during the peaks of the pandemic. The NHS suffered considerable staff shortages due to COVID 19 related illness and self- isolation periods. Interviewing carers was also difficult as they were without respite services for over a year. Carers had limited time to schedule an interview when caring full time for an adult with dementia, with extremely restricted support available to them due to social distancing measures. This entailed that the recruitment of both participant groups was very challenging. It was also not possible to speak to those living with dementia due to the pandemic setting. This is reflective of the restraints of the context and reflected upon in the methods and discussion chapters of this thesis.

Contents Table

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Abbreviations

ADL (Activity of Daily Living)

CASP (Critical Appraisal Skills Programme)

CRN (Clinical Research Network)

DH (Department of Health)

DOLS (Deprivation of Liberty Order)

GTN (Glyceryl trinitrate)

ICS (Integrated Care Systems)

ICP (Integrated Care Partnerships)

NHS (National Health Service)

NICE (National Institute for Health and Care Excellence)

NVivo (Qualitative analysis software)

PCR (Polymerase chain reaction)

PICO (Population, Intervention, Comparison, Outcomes)

PPE (Personal Protective Equipment)

PPI (Patient and Participant Input)

PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses)

R&D (Research and Design)

SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type)

Summary of thesis.

Chapter 1

The introductory chapter situates the thesis in the broader context of what is known about dementia, being a carer for someone with dementia, the experience of the hospital discharge process for a person living with dementia and their carer, and the importance of the topic of wellbeing in the light of the policy context. Through doing so, it identifies the gap in the evidence base that led to the development of research project outlined. The aims, objectives and research questions of the research project are included within this chapter: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

Chapter 2

This chapter outlines the method and findings of the systematic review which aimed to answer the question: What are the experiences of people with dementia, and their carers during the hospital discharge planning process? The search strategy, inclusion and exclusion criteria and data screening process, data extraction and synthesis process are detailed. The experience of patients and carers was synthesised separately. Omissions in the evidence base available are identified. Limitations of the systematic review are also identified.

Chapter 3

In chapter 3, the policy context of the research project is explored through an interpretivist approach to policy review (Bowen, 2009; Cardno, 2019). The context, content and consequence of the policy relating to the discharge of people living with dementia during the hospital discharge process is outlined (Bacchi, 2012) and analysed in the pre-pandemic context. The second section of the chapter considers how the policy issued from March 2020 during the pandemic impacted on the hospital discharge process for this demographic.

Chapter 4

How the methodology and appropriate paradigm for the research project was identified is outlined in chapter 4. How decisions regarding qualitative method were made is also discussed. Some of the challenges of recruitment and sampling are delineated. The role of patient and public involvement in the research is highlighted. The chapter discusses why the applied thematic analysis method (Guest, MacQueen and Namey, 2011) was chosen alongside the Appreciative Inquiry approach (Cooperrider and Fry, 2020). The decision to employ deductive analysis and utilise the theory of wellbeing identified by Kitwood and Bredin (1992) is justified. The importance of value, quality and reflexivity within the research process is discussed.

Chapters 5, 6, 7, 8 and 9

In chapters 5, 6, 7, 8 and 9 the findings of the applied thematic analysis (Guest, MacQueen and Namey, 2011) of the empirical interview study are presented. This includes the definition of wellbeing in this context and the expansion of the definition provided by Kitwood and Bredin (1992) of the three subthemes of Hope, Agency, and Personal Worth. The detail of these themes reveals the support needs of carers and patients, alongside the factors that support the maintenance of wellbeing. Agency is comprised of *processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*. Information regarding the participants and interviews is included. The findings of the analysis in relation to the Dream section of the Appreciative Inquiry (Cooperrider and Fry, 2020) cycle is also presented.

Chapter 10

In chapter 10 the findings from the systematic review synthesis are integrated with the findings from the empirical interview studies. Areas of agreement and divergence between the systematic review synthesis and the empirical analysis findings are identified. Further to this the impact that the pandemic may have in explaining the divergence is considered. There is discussion of how the findings have been used to begin the development of a framework aimed at ensuring the wellbeing of people living with dementia and their carers during the discharge process. Chapter 10 identifies the relationship between findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data analysis and the systematic review synthesis.

Chapter 11

In chapter 11 the key findings of the research project are discussed including how the findings align with the wider academic literature, how the social constructionist stance enabled a nuanced understanding of wellbeing, and the value of the Appreciative Inquiry process in identifying the changes required to promote wellbeing during the hospital discharge process. Lessons from the pandemic are pinpointed. The requirement for a change in focus towards the centralisation of wellbeing in the discharge process is discussed.

The impact of neoliberalist policies (Becker, Hartwich and Haslam, 2021; Mooney, 2012; Schrecker, 2016) on wellbeing during the discharge process are considered, together with the impact of COVID 19 and the implications of the findings for local NHS trusts, local councils, clinicians and relevant charitable organisations, such as Alzheimer's UK. Towards the end of the chapter, the strengths and limitations of the research project are considered and recommendations for future research made.

Chapter 12

Chapter 12 details the conclusions of the research project and implications of the findings.

A diagram of the thesis is included in figure 1.

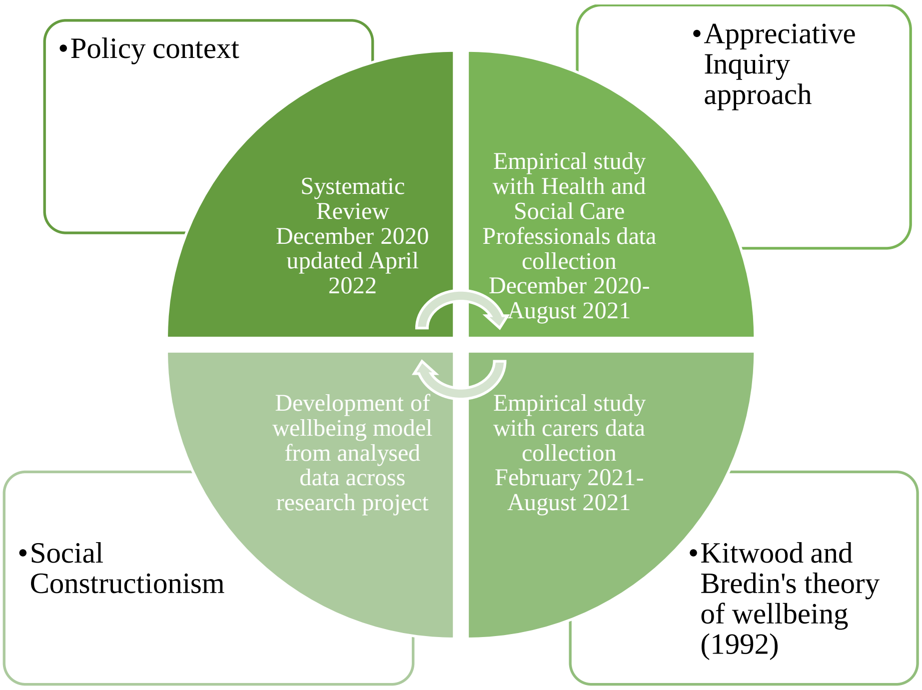


Figure 1. Diagram of thesis

The diagram represents the different components of the thesis visually including the time in which data was collected. The systematic review synthesis and findings from the empirical studies were instrumental in the development of the wellbeing framework. The Appreciative Inquiry approach (Cooperrider and Whitney, 2005) was used throughout the empirical research and the development of the wellbeing framework and is discussed extensively in Chapter 4. The theory of wellbeing developed by Kitwood and Bredin (1992) was used deductively during the analysis process and detail regarding this is presented in Chapter 4. The social constructionist ontology influenced all aspects of this thesis alongside the policy context which is outlined in Chapter 3.

Chapter 1. Introduction and literature review

1.1 Introductory preface

This thesis presents the findings of a qualitative exploration of the meaning of wellbeing for adults living with dementia and their carers during the hospital discharge process both immediately prior to and during the COVID 19 pandemic. The idea for this research project originated in November 2016, when myself and my supervisors, met to discuss aspects of hospital care for people living with dementia and the dearth of research evidence regarding best practice. Local nurse specialists identified the hospital discharge process as challenging for this patient-carer group and bereft of qualitative research focus. We could not have foreseen the 2020 COVID pandemic or the impact it would have on the research project.

Within this introduction, I will outline the research gap that became apparent as I carried out an informal scoping review of this topic during the research project's development in 2017, 2018 and early 2019. Identifying this gap allowed me to develop a research project which would be responsive and suitable to address the gap in the evidence base. The project had to be adapted to ensure compatibility with COVID 19 regulations in force during 2020 and 2021. Information pertaining to this is detailed within the methods chapter (4) of this thesis.

The concept of wellbeing for carers and people living with dementia during the hospital discharge process has not received the research focus required. The introduction will situate the thesis in the broader context of what is known about dementia, being a carer for someone with dementia, the experience of the hospital discharge process for a person living with dementia and their carer, and the importance of the topic of wellbeing. This will identify the gap in the evidence base that led to the development of research project outlined. The aims, objectives and research questions of the research project will be included at the end of the section and an overview of the structure of the thesis will be presented. I will begin with a reflective commentary regarding the origins of my interest in this subject and the background to this thesis.

1.2 Origins of this project

The origins of this project lie in my profession as a nurse and awareness of the complexities of the lives of people living with dementia and their carers. As a practicing nurse, I was employed in the hospital setting, caring for people living with dementia. I was aware of the difficulties often faced by carers and people living with dementia and particularly the complexities of hospital discharge. I was later employed on a project aiming to learn more about the experiences of people living with dementia in the hospital setting, with the end goal of creating a toolbox to support these individuals. Being involved with the project gave me a new perspective on what it was like to stay in hospital as a patient with cognitive impairment. I was able to view the hospital journey from both the patient, professional and carer perspective and thereby, witnessed the positive and negative elements of the hospital environment.

In my personal life, my grandfather is living with Alzheimer's disease and my mother in law's mother lived with Lewy body dementia. My best friend's mum also lived with dementia. Therefore, dementia is a presence in both my personal and professional life. I am aware of many of the difficulties around the hospital journey for people with dementia and their carers, and I have been the carer, on the end of the phone, trying to contact the correct hospital ward and locate my grandfather. On one occasion I made 22 phone calls to try and reach someone who was looking after my grandfather.

The experiences and perspectives of patients and carers have always been central to my professional practice. As a professional, I am also particularly interested in the opinions and knowledge of my colleagues in other disciplines. I believe strongly that patient, carer and professional opinion and input should be vital in shaping hospital and community health and social care services and policy, to meet the needs of all patient groups. All three groups should and must work together in partnership to enable safe and supportive care experiences and environments. Therefore, the importance of implementing a project focusing on the perspective of all stakeholders was evident to me.

When devising this project, I was informed by a supervisor that the dementia specialist team located at the local hospital had identified that there were problems with the hospital discharge process. I scanned the literature and discovered that there was limited qualitative evidence available about this topic which focused on the experiences of people living with dementia and their carers. I met with discharge co-ordinators and social workers who discussed their concerns about the discharge process. I knew the importance of creating an evidence base that could support the wellbeing of people living with dementia and decided to focus on this topic.

1.3 Context of the study

The hospital discharge process must be situated within the wider context of knowledge about dementia in both research and policy. Dementia is defined as a ‘syndrome associated with an ongoing decline of brain function’ (National Health Service, 2017), which includes: problems with memory; thinking; language; judgement and movement. The term can be used to include many individual categories of cognitive impairment, for example: mild cognitive impairment; Alzheimer’s disease or frontal temporal lobe dementia. The causes of dementia are not fully understood but appear multifactorial and complex. There is no current cure for dementia (Alzheimer's Society, 2019). How dementia has been understood, amongst academics and the general public, has undergone a radical shift in the last thirty years.

Originally pathologised as a neurological condition, it was identified by theorists such as Kitwood (1997), that the concept of dementia was also a socially constructed entity, characterised through social malignancy and depicted as a loss of personhood for the individual. The work of Kitwood (1997) challenged this dominant paradigm that categorized dementia as a medical condition leading to a loss of self through the deterioration of memory. Kitwood (1997) suggested that the practice of person-centered care and provision of holistic support for the individual living with dementia enabled the continuance of their personhood. This is in spite of the impact caused by the progression of the syndrome. Further to this, it was argued (Kitwood, 1997) that the negative attitudes displayed towards people living with dementia, by both society and the medical establishment, needed to change. It was contended (Kitwood, 1997), that positive ways of living with a dementia diagnosis needed to be prioritised. This fundamental shift in how dementia was viewed by the medical establishment and more broadly across society, led to revolutionary changes in both the care provided and the attitudes displayed towards people living with dementia. This positive advancement of the dementia paradigm coincided with significant increases in the numbers of individuals being diagnosed with dementia globally.

The World Health Organisation estimates the number of people living with dementia worldwide at 50 million. This figure is projected to increase to 75 million by 2030 and 152 million by 2050. It has been recognised that the vastly increasing numbers of individuals living with dementia, will lead to significant challenges for future health and social care structures internationally (Alzheimer's Disease International, 2017). In response to this, the World Health Organisation (2018) has issued guidance urging governments to develop comprehensive, multifactorial policy approaches, which address the enablement of sustainable and healthy living for this growing population group. In the UK, 1 in 3 people are expected to develop dementia in their lifetime and it is now the leading cause of death in the UK. The cost to the UK economy has been estimated at £ £34.7billion a year with predictions of a rise to £94.1 billion by 2040 incorporating costs to the NHS, social care costs and costs in unpaid care (Alzheimer's UK, 2019; London School of Economics and Political Science, 2019). It is apparent from the figures above, that the number of individuals living with dementia is already having a profound impact on the health of individuals and the economy of the UK. The importance of meeting the growing challenge of dementia prevalence has led to a significant policy response from the UK Government.

The Prime Minister’s Challenge on Dementia 2020 (Department of Health and Social Care, 2015), aimed to establish the UK as one of the best places to live globally with a dementia diagnosis. It aimed to encourage dementia friendly communities and support ongoing research into living well with dementia. Over 50 commitments were made within the policy paper and an evaluation of the success of those commitments is currently under review and has been anticipated since 2018. The publication (Deeks *et al.*, 2016) specifically addressed the requirement for support, in relation to wellbeing, to be available for both patients and carers in their day to day lives. This requirement was reinforced by a wealth of research, which has suggested that the impact of caring for an individual living with dementia can be profound and challenging (Feast *et al.*, 2016; Gao, Chapagain and Scullin, 2019; Sheehan *et al.*, 2021).

It has been established in academic literature that being a carer for someone living with dementia has a profound impact on all aspects of carer quality of life (Jones and Peters, 1992; Farina *et al*., 2017; Nuffield Trust, 2022). The Family Resources Survey (Department for Work and Pensions, 2022) identified that around 6% of the UK population are informal carers and around 1 in 8 people will be an informal carer in their lifetime (Carers UK, 2022). Whilst 60% of carers are female, carers over the age of 85 are predominantly male (House of Commons Library, 2022). Carer physical and mental health has been identified as significantly worse than the health of general population who do not care (Carers UK, 2021). During the pandemic in 2021, research was implemented via an online survey which included the responses of over 8,119 carers in the UK. The survey showed that carers were disproportionately affected with increased care responsibilities, and that significant loneliness was reported by 90% of the carers taking part in the survey (Carers UK, 2020; Carers UK, 2021). A report by Alzheimer's Research UK (2015) highlighted that the carers of individuals living with dementia, often experience social isolation and there can be a corresponding impact on their mental health. It is also established that there is increased financial, social, and physical burden on carers of people living with dementia, in comparison to other categories of carer (Brodaty and Donkin, 2009). It has been shown that there are categories of carer that face additional challenges, such as, carers for individuals with early onset diagnosis, and those from ethic minority backgrounds (National Institute for Health and Care Research, 2020). Therefore, it is important that government policy promptly addresses the needs of carers and people living with dementia.

1.4 UK carer policy

The UK government has issued guidance related to The Care Act (Department of Health, 2014a) which places a responsibility on local authorities to act in ways that support the wellbeing of carers. Local authorities must ensure the provision of a robust health and social care system, which values carer contributions and aims to support their wellbeing. This requirement ensures that there is the need for research to be available that can provide a vigorous evidence base to underpin policy initiatives.

There has been a significant amount of research focused on improving health and social care services and outcomes for people living with dementia and their carers (Fox *et al.*, 2017; Gibson and Yates, 2018; Richters *et al.*, 2018). Research has traditionally been segregated between being hospital or social care system focused and it has been acknowledged that there is scope for improvement within services in both sectors (Alzheimer's Research UK, 2015; Alzheimer's Disease International, 2017; Alzheimer's Research UK, 2018). Therefore, a research gap has opened in the transition from hospital to community-based care. The care provided in hospitals, for people living with dementia, has been heavily criticised in the UK (Alzheimer's Society, 2016). In response to this, guidance has been produced that aims to improve care standards, throughout the general acute hospital stay of people living with dementia (Dementia Action Alliance, 2018). Another identified problem related to the hospital discharge process is the education of nurses regarding care planning for people living with dementia and their carers.

1.5 Education of acute care nurses in dementia care.

There are skilled dementia specialist nurses present within acute care and their input has been shown to benefit people living with dementia and their carers (Griffiths *et al*, 2015). However, most acute nurses are not specialists in the care of people living with dementia and their carers. Collier, Knifton and Surr (2015) identified that there is a specific knowledge gap, within higher education institutions, in relation to the quality and quantity of undergraduate adult nurse education regarding people living with dementia and their carers. It has been identified that limited resources, and an absence of dementia knowledge within universities, has made incorporating robust dementia education into undergraduate programs challenging (Collier, Knifton and Surr, 2015). However, virtual training, educational programs incorporating the lived experience of people living with dementia and their carers, practice-based programs, and live model simulations were shown to have a positive impact on nursing attitudes, knowledge, self-confidence, and empathy (Alushi, Hammond and Wood, 2015; Maharaj, 2017; Kimzey, Mastel-Smith and Seale, 2019; Williams and Daley, 2021).

In 2007, Pulsford, Hope, and Thompson found that adult nurses were receiving an average of three hours of undergraduate teaching on the care of people living with dementia and their carers. Further to this, Traynor, Inoue and Crookes (2011) identified that there was no available framework to assess student nurse competency in the care of people living with dementia and their carers, leaving a gap in nurse education. A recent scoping review (Cariñanos-Ayala, Arrue and Zarandona, 2022) has shown that there is significant diversity among dementia education programs. The research found that the most common outcomes were knowledge, attitude and empathy but, due to the diversity of teaching methods, outcomes were not consistent. Furthermore, the only study which considered longitudinal outcomes identified that, after eight months, the education program had no long-term impact on attitudes, knowledge or empathy. Moreover, the review showed that adult nursing undergraduates are not being taught care planning in relation to people living with dementia or their carers, or about the structure of the services available for people with dementia in the system (Kim 2006). This is a significant gap in adult nurse education which will have a detrimental impact on the experience of people living with dementia and their carers at discharge.

1.6 Acute general hospital discharge process for adults living with dementia.

The general acute hospital discharge process has been identified as a particularly complex process for people living with dementia. A comprehensive factsheet released in November 2022 by Age UK (2022), outlines ways in which the discharge process can require complex decision making around discharge destination. This may incorporate capacity assessments, financial considerations, significant family input and the contribution of a multitude of clinicians, services, and assessment processes. Although these complexities may be involved in any discharge process, the nature of potential frailty, and fluctuating capacity in particular, can make the discharge process for people living with dementia significantly more complex (Stockwell-Smith *et al.*, 2018). Failings in the standards of care provided in hospital, and poor hospital discharge experiences, have been widely reported for older adults generally and for people living with dementia specifically (Healthwatch, 2015; Age UK, 2016; Macmillan, 2016). A report into the care provided during general and acute hospital discharge for people with dementia (Alzheimer's Society, 2016), identified a wealth of failings. These included high numbers of people living with dementia experiencing delayed discharges and significant numbers continuing to be discharged at night. The negative impact that poor hospital discharge experience has on patient outcomes has been illustrated in previous research findings (Ray, Ingram and Cohen-Mansfield, 2015) and highlights the importance that research is undertaken, which addresses how the hospital discharge process can be improved.

It is important to note that adults living with dementia may be admitted to inpatient psychiatric care for assessment, care planning purposes or changes to treatment plans (Wolverson *et al*, 2022). Discharge from these facilities is comprehensive, specialist and guided by mental health professionals trained in the care of adults with psychiatric conditions (Gondhalekar *et al*, 2021). However, the discharge process from acute general hospitals, for people living with dementia, will rarely receive the benefit of the specialist skills and knowledge of psychiatric professionals.

The Health Foundation (2023) defines ‘acute care’ as when ‘a patient receives active, short-term treatment for a condition.’ It further defines this as including ‘treatment for a severe injury, period of illness, urgent medical condition, or to recover from surgery.’ This context is representative of the hospital discharge process as defined in this thesis and is not to be confused with the specialised psychiatric discharge process.

There are several specific conditions that may cause a person living with dementia to be admitted to hospital. Studies have identified that being admitted to an acute hospital for a person living with dementia is rarely connected with their dementia diagnosis (Natalwala *et al*, 2008; Chang *et al*, 2015). Longitudinal quantitative research has identified that the most common reasons for a person to be admitted to an acute general hospital are: ‘acute delirium; newly onset stroke; pneumonia; fall-related hip fracture; and urinary tract infection’ (Natalwala *et al*, 2008, p. 503). Chang *et al* (2015) identifies that the reasons behind hospital admission for this demographic group, reveal that many community-based individuals living with dementia are vulnerable to dehydration, falls and bronchial issues.

Long *et al* (2013) identified that due to the reasons that people living with dementia are admitted to hospital, they are vulnerable to a number of adverse effects. Pressure ulcers, falls, dehydration, delirium, and hospital acquired infections are all likely to be experienced by people living with dementia who are admitted to hospital (Long *et al*, 2013; Fog, Griffiths, Meredith and Bridges, 2018). One of the reasons for experiencing these adverse effects are that people living with dementia are likely to be experiencing poor mobility and cognition following a fall, or when experiencing a health diminishing condition, such as pneumonia (Kosse *et al*, 2015).

Another significant issue that arises during inpatient stays for people living with dementia is the under treatment of pain. Tsai, Brown and Inder (2022) identified that there is an underusage of pain assessment tools for people living with dementia in hospital. Long *et al* (2013) identified that these adverse events are largely caused by both direct and indirect causes of harm. Direct causes include ineffective assessment and treatment, indirect causes include discrimination and limited availability of trained staff (Long *et al*, 2013).

In the following section I will outline the stages of the discharge process and consider why there might be some failings within the discharge process. Figure 2 depicts this process visually.

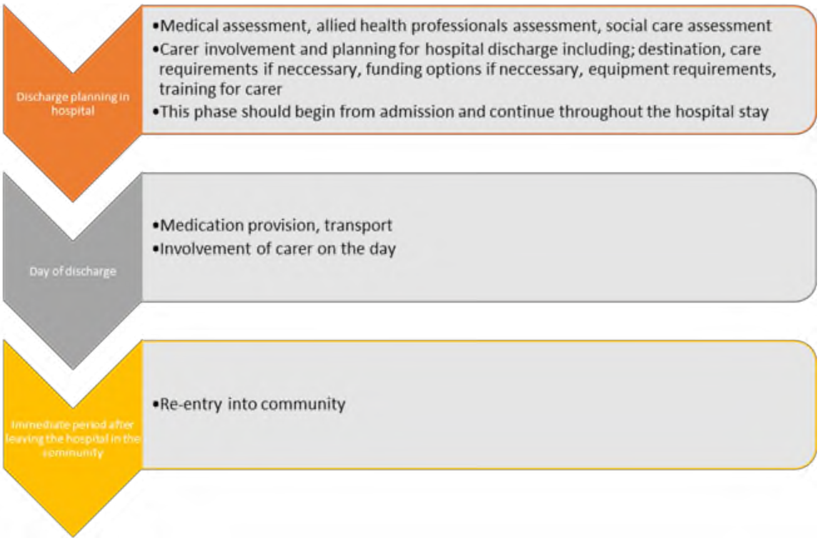


Figure 2. Outline of the discharge process.

The reasons behind the failings identified in the hospital discharge process are multifaceted (National Audit Office, 2016; Kings Fund, 2017). They cannot be simply distilled to issues with funding, staffing, or training, although weaknesses in all of these areas, have been identified as contributing to failings in the hospital discharge process for older adults and adults living with dementia. Previous research has identified that discharge must be viewed as a process which extends beyond the patient leaving the hospital and incorporates their experience in the community in the immediate post-hospital discharge period (Mockford *et al*., 2017). Therefore, there are two distinct phases to the discharge process: the hospital-based segment and the corresponding community phase. I will consider both segments of the discharge process separately, as this is the approach most often taken by research literature and policy documents. However, the issues and complexities of both the hospital and community phase of the discharge process, are fundamentally related to one another and cannot stand in isolation (Care Quality Commission, 2018).

The requirement to ensure a positive hospital discharge experience for people living with dementia and their carers, has long been acknowledged in both research literature, and government policy (Cox, 1996; Department of Health and Social Care, 2013). There are several identified reasons why people living with dementia and their carers are experiencing negative hospital discharge experiences. Many researchers have identified that the problem may be partly attributable to the medicalised setting itself. There is a well-established literature highlighting the dominant medical model that permeates health care (Illich, 1974; Stacey, 1988; Nettleton, 2006) and is associated with reductionist and paternalistic care provision, which nullifies the potential social causes of ill health. The impact of the dominance of this reductionist and paternalistic model on health provision, continues to be analysed in academic discourse in the modern technological era (Morley and Floridi, 2020; Varley and Varma, 2021). The ongoing role of iatrogenesis as applicable within dementia care has been a recent demonstration of the ongoing relevance of these theories (Morris, McCloskey and Bulman, 2022).

Other research has suggested that it is not only the dominance of the medical model, and the paternalistic approach of the NHS, which can lead to negative outcomes and experiences of the hospital discharge process, but also the organisational structure of the hospital. Barry and Yuill (2011) argue that the organisation of the hospital itself is designed to undermine patients and prevent their individual requirements from being asserted. This corresponds with Goffman's (1961) seminal argument that the needs of the institution, whether medical, educational or bureaucratic, are always placed above the needs of the individual, and that a by-product of this is the suppression of subjective needs. Goffman (1961) elaborated further that the 'total institution', such as the hospital context, often requires the individual to comply with its own procedures and rules and cannot accommodate individual requirements. Recent theorists have built upon this work and identified the ways in which the modern hospital continues to correspond to the concept of the total institution (Jenkins, Burton and Holmes, 2022). The way in which the electronic patient record, and drug administration computerized systems, operate as mechanisms of control in the twenty first century underscores the continuing relevance of these theoretical viewpoints (Jenkins, Burton and Holmes, 2022).

The work of Foucault (1975) builds on this argument, to infer that institutions tend to become focused not on the merit or value of individual actions and outcomes, but simply on whether individuals are following the rules of the institution. A brief overview of the literature relating to the hospital discharge experiences of carers and people living with dementia, reveals that these themes emerge time and again in reports (Care Quality Commission, 2018) and research findings (Mockford, 2015). The medical model and needs of the hospital organisation appear to trump patient requirements consistently, even though policy and research findings clearly require a different, individualised approach to patient care and discharge processes (National Institute for Health and Care Excellence, 2015; Dementia Action Alliance, 2018).

It has also been noted that the neoliberal agenda within the healthcare system, whereby responsibility and risk have shifted away from the state and towards the individual by cutting public funded services, care and organisations, has impacted on the discharge process (Harvey, 2007; Mooney, 2012; Venugopal, 2015) This has led to reduced services and an emphasis on the individual making choices, rather than receiving support either financially or through care (Schrecker, 2016). This reduction in capacity has led to individuals and families having to, 'fend for themselves', during the discharge process with limited input from either the community, or hospital services, into organising the transport, place of discharge, equipment required etc., as these are deemed to be largely the responsibility of individual and their families (Venugopal, 2015). Therefore, the responsibility for the discharge process has been shifted to the individual being discharged, and when this individual is living with dementia, it leads to a complicated and stressful process for the carer and individual, with little support available.

Factors that contribute to negative and positive experiences of hospital discharge, for people living with dementia and their carers, will be explored further within the systematic review section of this thesis. A summary of some of the key issues identified frequently in the literature include: the exclusion of carers and people living with dementia from the discharge decision making process (Bauer, Fitzgerald and Koch, 2011; Mockford *et al.*, 2017); poor community service provision and social care involvement within the discharge process (Kable *et al.*, 2015; Jamieson *et al.*, 2016); an absence of support for carers of adults living with dementia (Shyu, 2000; Coleman and Roman, 2015; Kuluski and McGeown, 2017); the privileging of hospital needs above patient wellbeing and patient centered care (Norman, 2003; Huby et al., 2004; Digby, Lee and Williams, 2018b) and insufficient discharge planning procedures and policies during this period (Sewter, 2014; Gilmore-Bykovskyi, 2017).

In the UK, guidance around the importance of robust discharge planning and the importance of including carers and patients in the process, has been explicitly available since 2015 (National Institute for Health and Care Excellence). This guidance (National Institute for Health and Care Excellence, 2015) applies officially to England only. The devolved governments of Wales, Northern Ireland and Scotland are responsible for approving the applicability of National Institute for Health and Care Excellence (NICE) guidance on an individual basis. However, it is standard practice to adopt the guidance, after review, within the devolved nations of Wales and Northern Ireland (National Insititute for Health and Care Excellence, 2013). Although not officially bound to follow the guidance, clinicians and commissioners in Scotland are guided to consider NICE guidance when making decisions, and in their practice (Kohli and Tannahill, 2009). Scotland has an official body known as SIGN (Scottish Intercollegiate Guidelines Network). However, their only available guidance in relation to the discharge process is a discharge document from 2012. This guidance is not specific to people living with dementia and is limited (Scottish Intercollegiate Guidelines Network, 2012).

Since publication of the guidance, no new UK research has emerged to assess whether there has been an impact on discharge practices within the UK. However, information from the National Audit Office (2016) has suggested that improvements in the discharge planning process have not occurred since implementation. Findings from the National audit of dementia (Royal College of Psychiatrists, 2017, p. 67) identified that 1 in 4 carers are not being given any notice of impending hospital discharge. This suggests that the involvement of carers during the discharge decision making process is still problematic. These findings are further supported by the Care Quality Commission (2018), who have also critiqued the hospital discharge process, and identified several improvements which should occur, including greater integration between health and social care structures (Care Quality Commission, 2018).

The need for further integration between social and healthcare services, has been discussed at length (Age UK, 2016; Kings Fund, 2017). A lack of capacity and resource; an absence of joined up working due to the separation of governance; poor leadership, the prioritisation of targets and commissioning objectives; fears around information sharing and a social care funding crisis; have all been implicated in failings within social care provision during the hospital discharge process. Delayed discharges and a failure to complete the necessary assessments prior to discharge have been highlighted as particular issues (Age UK, 2016). The Nuffield Trust (2021) identified that between 2010 and 2020 there was a 96% increase in delayed hospital discharges. The number one reason for delayed hospital discharge was the shortage of available care packages in the community. Following this, delays in acute treatment within the hospital and a shortage of care home placements were identified as being responsible for delayed discharge processes (Nuffield Trust, 2021). Interestingly, data on the causes of delayed discharges has ceased to be collected centrally since 2020 (Limb, 2022). The reason this data is no longer collected is unclear.

Although the NHS Long Term Plan (NHS England, 2019), aims to overcome the absence of joined up working by placing social workers on hospital wards, the continued privileging of funding for healthcare services suggests that the medical model is still prioritised above social understandings of health and wellbeing. This should be reassessed in the current context of an aging population. This is particularly important in the light of evidence suggesting that pressures on social care funding directly impact on mortality rates for this age group (Watkins *et al.*, 2017). The historical divide between health and social care funding and practice, has been increasingly criticised. There have been calls for a new funding and commissioning model (Care Quality Commission, 2018, p. 6), which acknowledges the vital role that social care services play in the hospital discharge process and challenges the notion that the two services can be separated. The UK Government's ongoing failure to deliver the green paper on social care, whilst simultaneously delivering The NHS Long Term Plan (NHS England, 2019), highlights the challenge of social care provision and the continued prioritisation of healthcare policy.

The Health and Care Act (2022) established Integrated Care Boards and integrated Care Partnerships (ICP) as legal entities in July 2022. The Integrated Care Systems, as outlined in the white paper (NHS England, 2022a), aim to integrate health and social care in relation to commissioning and practice. This change in policy approach has been largely welcomed but it is too early, following the implementation of this policy, to identify any outcomes in relation to the hospital discharge process. However, in June 2022 the then Secretary of State for Health and Social Care, and the Secretary of State for Levelling Up, Housing and Communities, issued an invitation for expressions of interest to become a Discharge Integration Frontrunner site to Integrated Care Systems (ICS). The objective of the Discharge Integration Frontrunner Sites is stated to be developing and testing radical new approaches to post-acute care, that see patients discharged to, 'the right place, and with the right support, in a safe and timely manner' (Department of Health and Social Care, 2022a, p.1). One of the aims of the discharge integrator front runner program is for ICS's to 'design and test new service models, such as the delivery of a more integrated model for intermediate care across existing health and social care portfolios' (Department of Health and Social Care, 2022a, p.1). The substance of these new models is not evident. Whether these models will be able to address the issues of delayed discharge and the problems outlined within this chapter is also unknown.

Although the Care Act (Department of Health, 2014) calls for local authorities to promote the wellbeing of carers and care receivers, in reality the reduction in social care funding (Age UK, 2016) contributes to social care failings and increasingly poor discharge experiences. Research findings (Mockford *et al.*, 2017) have shown that appropriate, robust, community based social care services are often not available at the point of discharge for people living with dementia. This finding is evident, even though there is a statutory duty on local authorities to provide these services under The Care Act (Department of Health, 2014). There is a significant gap between policy, theory, and current practice, for both health and social care aspects of the hospital discharge process. While it is evident that, within the context of social care, some of this gap is due to funding issues, the research findings briefly mentioned above suggest that there is a more complex overall picture of why the hospital discharge process is so often a negative experience for this demographic, which goes beyond just care staff availability and funding concerns (Bauer *et al.*, 2009). The announcement, in November 2022, by the Secretary of State for Health and Social Care that £500 million will be made available to support both social care provision, and bed capacity in hospitals, was not regarded by groups such as Age UK, or The Kings Fund, as sufficient to address the systemic problems within the discharge process (Department of Health and Social Care, 2022b; Croner-i, 2022). The funding was criticised as being merely a stop gap, unable to address the problems inherent to the hospital discharge process.

1.7 The research gap

There is limited research available that addresses the discharge process specifically for people living with dementia and their carers. It is important that qualitative research is available for this topic and this carer dyad to enable a deeper understanding of the complexity of the hospital discharge process experience, and the challenges faced by this population (Johnson and Waterfield, 2004). It is important to access lived experience to understand the intricacies of the process beyond what quantitative data can indicate. There has been little qualitative research into why the gap between policy, research findings and practice exists for this patient and carer group.

It is important that qualitative research is available for this topic and this carer dyad to enable a deeper understanding of the complexity of the hospital discharge process experience and the challenges faced by this population. It has been identified in numerous studies that more research around the process is required (Shippen, Young and Woods, 2011). Available research findings often focus exclusively on either hospital based or social care aspects of hospital discharge (Cox and Verdieck, 1994). This approach has historically made sense as these two sectors have been funded separately and operated separately. However, it is my contention that this is a flawed perspective of a process that is fundamentally co-dependent. This is even more applicable following the introduction of ICS's and new ways of collaborative working between the sectors.

The study will avoid this shortcoming by considering both the hospital and social care elements of the discharge process simultaneously. Further to this, available research is often focused on the involvement of patients and carers and not on factors that ensure a positive experience and outcome of the discharge process (Shippen, Young and Woods, 2011). This is a significant issue as it has been identified that some patients do not want to be explicitly included in decisions made during hospital discharge (Huby *et al.*, 2004). Therefore, a greater research emphasis on identifying the holistic factors crucial to a positive discharge experience, and potential improvements to current discharge processes, needs to be adopted to address the gaps in the current evidence base.

Although policy is available that addresses transitions from hospital to home or residential care (National Institute for Health and Care Excellence, 2015) for adults with social care needs, the requirements of individuals living with dementia are not specifically addressed. This is problematic as people living with dementia, and their carers, may have different needs to other patient groups, particularly in relation to capacity assessments. An apparent juxtaposition between health and social care policy and practice is the importance of patient and carer wellbeing. Although the promotion of wellbeing is strongly established in policy and law (National Institute for Health and Care Excellence, 2015; Department of Health, 2014a; NHS England, 2019) it has not yet received much research activity and does not appear to be explicitly addressed in health and social care practice.

1.7.1 Why wellbeing for people living with dementia and their carers deserves further attention.

The importance of patient and carer wellbeing has not featured prominently in research focusing on hospital discharge for people living with dementia. Carer and patient wellbeing often appear to be overlooked in favor of hospital concerns, such as the pressure to facilitate timely discharge (Stockwell-Smith *et al.*, 2018) and mitigation of risk (Emmett *et al.*, 2014). No research has been conducted which considers how patients, carers and health professionals understand the concept of wellbeing or whether it is currently utilised in hospital discharge practice. Research findings have argued that wellbeing is a holistic concept which can be contradictory (Dodge *et al.*, 2012; La Placa, McNaught and Knight, 2013) and includes aspects of the physical, psychological, social and spiritual. In correspondence with this, the UK Government has defined wellbeing as including ‘physical, social and emotional dimensions’ (Department of Health, 2010, p. 13) of health. This is in harmony with the World Health Organisation definition (2019) and it has established its commitment to the embedding of wellbeing within future policy initiatives and publications (Department of Health, 2014c). Further to this, the UK Government has identified that wellbeing and health are intrinsically linked and highlighted that there are huge gaps in the evidence base concerning wellbeing (Department of Health, 2014b). One particular gap identified is the paucity of evidence around what increases wellbeing in different contexts and during different processes. This is a significant oversight, as wellbeing has been identified as a better health indicator than the quality-of-life index. This quantitative measurement of wellbeing, which features standard indicators, has been ubiquitous in modern health and social care research. It has been critcised as overly prescriptive (Ferrans and Powers, 1985) and lacking in flexibility. Further research into understanding the term wellbeing may be able to address this criticism. It has been argued that ideas of patient and carer wellbeing should be central to all health and social care decision making (Department of Health, 2014c). Recently, the requirement for further research exploring and evaluating the concept of wellbeing, in different settings, has been recognised by UK research councils (Economic and Social Resarch Council, 2019).

Although national policy and guidelines request the support of patient and carer wellbeing during the hospital discharge process (NICE, 2015), there is no guidance available addressing how to achieve this in practice. In the early scoping exercise, no research was identified which explicitly considered how ideas concerning wellbeing impact upon hospital discharge practice. Nor was there any exploration of how people living with dementia, their carers, or health and social care professionals. understand wellbeing in this context. Therefore, a requirement for research which addressed this gap, and identified the tenets of the concept of wellbeing, and what supports its maintenance was evident. In the next section, I will address the aims and objectives of this research project. I will include the caveat that this research project went through many iterations and had multiple protocols across two qualitative studies requiring NHS Research Ethics committee approval, and HRA approval, a systematic review, a university protocol, and a post COVID 19 protocol.

1.8 Research aim and objectives

Given the identified evidence gap, the aim of this research project was to explore the facets of wellbeing for people living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. The research project was planned in 2019 before the pandemic and adapted to the restrictions required by COVID 19. Further detail of the changes in method and focus that the project underwent, and the opportunities and restrictions imposed by the pandemic, are outlined in the methods chapter. A secondary aim included contributing to the developing evidence base available to policy makers, and clinical professionals, in relation to the wellbeing needs of this dyad during the hospital discharge process in the post COVID 19 climate. This included the aim to define the term wellbeing in this context.

The objectives include:

1. Conducting a qualitative systematic review to identify and synthesise available evidence, regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. *What are the experiences of people living with*

dementia and their familial carers, during the hospital discharge planning process?

2. Identifying factors (environmental, organizational, resource or social) that impact the physical, emotional, and social wellbeing of people living with dementia and their carers, during the hospital discharge process, through interviews with health and social care professionals and carers.

3. Exploring if, and how, the wellbeing and support needs of people living with dementia and their carers are addressed in current hospital discharge practice, or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

4. Identifying how guidance from 'COVID 19 hospital discharge requirements' (Department of Health and Social Care, 2020a) impacted on the discharge process during the COVID 19 pandemic.

5. Developing a framework based on the perspectives of carers and healthcare professionals to ensure wellbeing, in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Ultimately the research questions I adopted evolved during the span of the research project and the impact of the COVID 19 pandemic and became: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

1.9 Summary of chapter and outline of structure of the thesis

This chapter has outlined the wider academic and political context in which this research project was designed and implemented. The importance of research that addresses the requirements of people living with dementia and their carers, has never been greater due to the rising number of people living with this condition. The perceived failings of the hospital discharge process, and the emerging importance of the term wellbeing in policy documentation, has revealed the research gap, justifying the research aim and objectives of this research project. Moreover, the recent changes to the health and social care context in relation to the establishment of ICS's and ICP's, and the impact this may have on the hospital discharge process for this carer dyad, denotes the importance of this research project in aiding to develop the evidence base in this area.

The next section of this thesis details the method of the systematic review, and the synthesis of the available qualitative research regarding the evidence relating to the experience of people living with dementia, and their carers, of the hospital discharge process. The limitations and conclusions of the systematic review are discussed, enabling a comprehensive overview of prior research in this topic area. Subsequently, the methods section of this thesis details how the research project was implemented and how the author made choices about methodology and method. Following this, the data itself is presented, including information regarding the participants of the study. The final section of this thesis examines what the data reveals about wellbeing during the hospital discharge process for this carer dyad, how the data develops the findings of the systematic review, the implications for policy makers, National Health Service Trusts, and clinicians, and a potential framework for supporting wellbeing during the discharge process in the post COVID 19 context.

Chapter 2. Systematic review

2.1 Introduction to chapter

This chapter presents a systematic review of the available qualitative evidence concerning the hospital discharge process. In the previous chapter, it was identified that there have been a number of concerns raised regarding the standard of hospital-based care for people living with dementia (Alzheimer's Society, 2016), including concerns with regard to the discharge process (Healthwatch, 2015). Despite the identification of hospital discharge as problematic for people living with dementia, limited research has focused on the hospital experience or hospital discharge for this patient group. Therefore, the experience of people living with dementia during this process has not been comprehensively investigated.

The lack of evidence relating to patient experience of discharge, combined with evidence of a negative impact on wellbeing following hospital admission, suggests that clinicians, stakeholders, and commissioners, do not have access to a patient informed evidence base that can enable them to support wellbeing during hospital discharge. Therefore, it is vital that evidence indicating the factors that can safeguard wellbeing is synthesised to provide commissioners and clinicians with the information required to support patients during hospital discharge.

A qualitative systematic review of the experiences of people living with dementia and their carers during the hospital discharge process, has not been previously undertaken to the knowledge of the researcher. Therefore, this review was undertaken to clarify the key literature related to the research topic; identify how the thesis expands upon what is already known about the topic, prevent duplication of research; and allow for a more nuanced approach to any planned empirical work (Clark, 2016).

The systematic review aimed to address the following questions:

2.2 Primary aim

What are the experiences of people living with dementia, and their carers during the hospital discharge planning process?

2.2.1 Secondary aims

Identify the key factors that should guide health care professionals in safeguarding the wellbeing of patients living with dementia, during the discharge planning process from hospital?

Identify any omissions in the evidence base, regarding the experience of people living with dementia, and their carers during the hospital discharge process.

The primary aim and secondary aims chosen enabled the broad identification of the experience of hospital discharge, alongside the factors that ensure wellbeing for people living with dementia during the discharge process. The identification of any omissions, within the evidence available, regarding the experience of the discharge process was also chosen to highlight any gaps evident. The methods employed in the systematic review process, including the search strategy, shall now be outlined. The protocol for the systematic review was published via Prospero.

2.3 Methods of systematic review

2.3.1 Protocol

The protocol for the systematic review was registered with Prospero (registration number: CRD42019131815) Further details can be found on the Prospero website. The original plan for the systematic review and the systematic review protocol are included in the appendices.

2.3.2 Search strategy

Search terms included both primary qualitative and mixed methods studies. Both published and unpublished or grey literature was included from 1990 to December 2018 in the first instance. I identified that care for people with cognitive impairment, including dementia, before 1990 would not be compatible with modern person-centred care approaches (Kitwood, 1997). The systematic review searches were re-run to be inclusive of all publications until 1 April

2022 in the second instance. The search terms and number of identified articles for each database were recorded. The following sources were searched to identify published literature using Boolean operators including truncation: Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present; Embase (Ovid); CINAHL (EBSCO); PsycINFO; Scopus; SCIE: Social Care Online; Pubmed; Proquest; Cochrane; Web of Science. The search terms outlined in table 1 were utilised to search the above sources. The terms were adjusted to meet the requirements of the specific data base. The reference lists of all included studies were hand searched to identify further relevant studies.

Table 1. Search terms utilised in the database search process.

Table 1						
Sample (patient)	**Sample (carer)**	**Sample (Dementia)**	**(Phenomena of Interest) Discharge from hospital**	**Design**	**Design Evaluation Experience**	**Research Type**
Adult	Family	Dementia	Return home process	Interviews	Perception	Qualitative
In-patient	Relative	Cognitive Impairment	Leaving hospital	Focus groups	Perspective	
Patient	Carer	Confusion	Discharge planning	Observation	View	Mixed methods
	Family Carer	Alzheimer’s			Experience	
	Family carer	Frontal temporal lobe dementia			Insight	
	Informal carer				Opinion	
	Carer					
	Spouse/wife/ husband					
	Child/daughter/ son/grandchild					

The SPIDER (Sample, Phenomenon of Interest, Design, Evaluation, Research type framework) (Cooke, 2012) outlined in table 2 was utilised in the development of the search strategy. The SPIDER framework has been recognised as more appropriate to systematic review search strategy design for qualitative reviews than the quantitatively focused PICO (Population, Intervention, Comparison and Outcomes) (Methley *et al.*, 2014). It enables the search to focus on the characteristics important to qualitative research, enabling the search to access the correct research designs, samples, and topics.

2.3.3 Inclusion and exclusion criteria

Table 2. SPIDER framework and inclusion criteria for review

Table 2	
Sample	Patients and carers of adults with cognitive impairment
Phenomena of Interest	Discharge from hospital process for patients and carers/relatives
Design	Interviews, focus groups, case studies, ethnographies, observational studies,
Evaluation	Experiences
Research Type	Qualitative, mixed methods

Table 3. Inclusion and exclusion criteria beyond SPIDER framework

Table 3		
	Inclusion Criteria	Exclusion Criteria
Publication	Peer reviewed journals, reports, audits, conference proceedings, unpublished thesis	Opinion pieces, editorials
Language	English language	Any other language

2.3.4 Data screening process

The titles and/or abstracts of studies retrieved using the search strategy and those from additional sources, were screened by myself in entirety (n= 6342). The second reviewer (CA) screened 20% of the results to ensure that no studies were being incorrectly excluded or included at that time (n= 1268). Studies that did not meet the inclusion criteria outlined in table 2 and table 3 were excluded (n= 6123). Decisions about inclusion and exclusion of studies, were decided in a series of meetings between the two reviewers where disagreements regarding inclusion were discussed to achieve consensus. The PRISMA (Preferred Reporting Items for Systematic Reviews and Meta-Analyses) flow diagram outlines the decisions made. The full texts of eligible studies were retrieved and assessed in full by the primary reviewer to ensure they met the inclusion criteria as outlined in the PROSPERO protocol (n= 219).

After the re-run of the searches in 2022, (n=2,579) articles were returned and entered into an endnote file for review. The titles and/or abstracts of studies retrieved using the search strategy, and those from additional sources, were screened during this update. The full text of 35 eligible studies was retrieved and assessed in full.

2.3.5 Data extraction

The data was extracted using a customised electronic data extraction form, tailored to the qualitative systematic review methodology, from the National Centre for Biotechnology Information (2011). The data extracted included: review authors; title and year; aim; study design; participant information (includes staff, carer or patient); inclusion and exclusion criteria; setting; design; summary of content and findings including themes; quotes; strengths and limitations; recommendations and reviewer comments. An example is included in the appendix (Chapter 14, Item 11).

2.3.6 Quality assessment

Risk of bias and the methodological quality of each study was assessed using the Critical Appraisal Skills Programme tool (2018) (CASP) specific to the design of the research assessed.

2.3.7 Meta ethnography synthesis process

In determining how to synthesise the studies, it was decided to use the method of meta ethnography (Noblit, Hare and Hare, 1988) due to the ability of this method to move beyond the findings of an original study to identify overarching theories, patterns and processes. Meta-ethnography has been characterised as different from other qualitative synthesis approaches. The systematic reviewer uses a translation synthesis to explore the theorised findings, such as themes or concepts, from the initial study alongside the raw data to transcend the findings of the individual studies, and create a new synthesis (Noblit, Hare and Hare, 1988). Other author's interpretations of the meta ethnography process were used to guide the synthesis (Britten *et al.*, 2002; Campbell *et al.*, 2012). The worked examples in the papers by Campbell *et al.* (2012) and Britten *et al.* (2002), helped illuminate the method relevant for developing the 'line of argument' synthesis central to meta-ethnography, and which was implemented in my own review. The seven steps outlined were used as a guide to the process: getting started; deciding what is relevant to the initial interest; reading the studies; determining how the studies are related; translating the studies into one another; synthesising translations and expressing the synthesis (Noblit, Hare and Hare, 1988; Britten *et al.*, 2002; Campbell et al., 2012).

1. Getting started: revisiting the original protocol for the study and ensuring that the papers selected for final inclusion addressed the research question.
2. Deciding what is relevant to the initial interest: papers were assessed to ensure that they could contribute appropriate data to the subject of the systematic review.
3. Reading the studies: studies were read at least twice by myself to develop familiarity with the methods and findings of the papers. Data was extracted into an excel table, in accordance with the systematic review process.
4. Determining how the studies are related: relationships between the papers were identified with common occurring themes selected.

During the data extraction process, the key themes and findings of the paper were entered into a spreadsheet. These themes and findings were then examined further and entered into a separate spreadsheet, so that relationships between the studies could be visually identified. All identified themes and findings were re-read and the key overarching themes that were common across the studies were extracted. This was a challenging process due to the high number of studies included, and the wide range of experiences for carers and patients. An example of how this was achieved is included in table 4 below.

Table 4. Determining how studies are related.

Table 4
Theme: Carers excluded from the discharge process
Bauer, Fitzgerald and Koch (2011) Carers not invited to discharge meetings
Telford (2015) Carers felt unheard with health and social care staff making decisions without their involvement
Coleman and Roman (2015) Carers not recognised as members of the health and social care team

Most papers key findings translated into one another readily. For example, the exclusion of the patient from the discharge process, the need for availability in relation to community services, and the requirement for more robust discharge policies and procedures. The included papers health and social care, geographical, funding and system settings were diverse. However, there were broad commonalities in patient experience, and in the recommendations for the improvement of the discharge process based on individual study findings. An example of this is shown in the appendices (Chapter 14, Item 12)

5. Translating studies.
6. Synthesising translations
7. Expressing the synthesis

It is difficult to explain the process of synthesis as the qualitative process cannot be broken down into a set of generic steps. This has been identified previously (Britten *et al.*, 2002). The themes identified were grouped into separate areas and overarching themes identified. The author checked that each theme fitted into each overarching theme and re-read the original studies to ensure that the themes reflected the findings of the all the included papers.

2.4 Results

2.4.1 PRISMA flow diagram

Figure 3 represents the PRISMA flow diagram and shows the process of identifying relevant research articles for inclusion in the systematic review. A table detailing a sample of the extracted data from the original included studies is located in the appendices (Chapter 14, item 11).

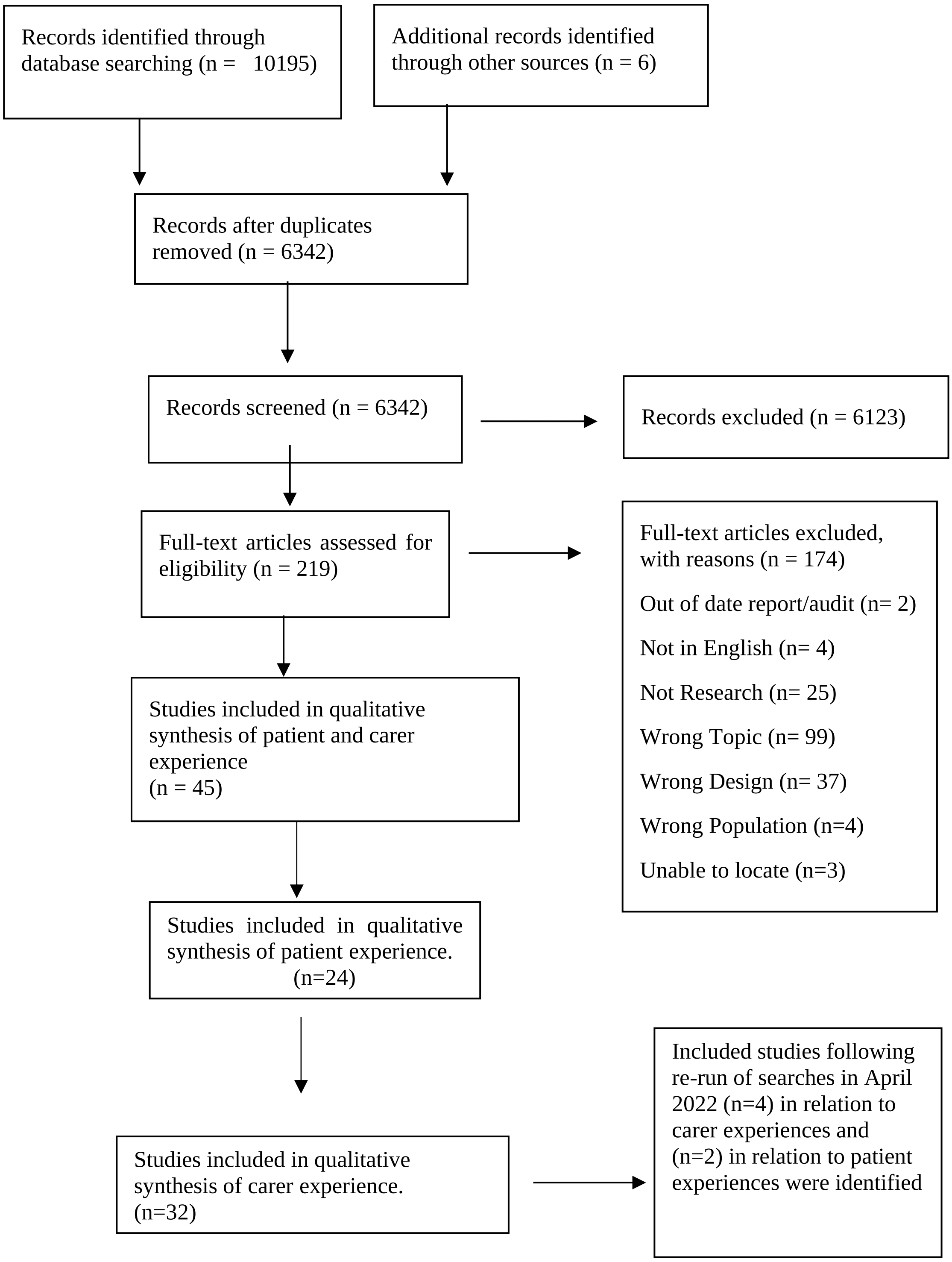


Figure 3. Prisma flow diagram of included and excluded studies

2.4.2 Patient experience synthesis

24 articles (Boaden, 2016; Bauer *et al.*, 2011; Bauer, Fitzgerald and Koch, 2011; Cumbler, Carter and Kutner, 2008; Coleman and Roman, 2015; Deeks *et al.*, 2016; Dyrstad, Laugaland and Storm, 2015; Digby, Lee and Williams, 2018b; Emmett *et al.*, 2014; Gilmore-Bykovskyi, 2017; Huby *et al.*, 2004; Jamieson *et al.*, 2016; Kable *et al.*, 2015; Kadushin and Kulys, 1994; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Kuluski and McGeown, 2017; Macmillan, 2016; Norman, 2003; Parliamentary Health Service Ombudsman, 2016; Poole *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Rhynas *et al.*, 2018; Telford, 2015) were included in the synthesis of patient data with 10 articles originating from the UK, Seven from Australia, five from the USA, one from Canada, and one from Norway.

17 of the studies included are primary research studies involving qualitative methods. Five are case studies (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016).

Following the re-run of the searches in 2022, one case study and one primary study (Department of Health and Social Care, 2015; Schreiber, Powell and O'Dowd, 2018) in relation to the experience of patients was included. A further two systematic reviews (Pritchard *et al.*, 2020; Richardson *et al.*, 2019) were identified and are discussed in the introduction.

2.4.3 Carer synthesis

32 articles were included in the synthesis in relation to carer experiences (Bauer, Fitzgerald and Koch, 2011; Bauer et al., 2011; Bloomer *et al*, 2016; Coleman and Roman, 2015; Cooper and Deeks, 2012; Cox, 1996; Deeks *et al.*, 2016; Dyrstad, Laugaland and Storm, 2015; Emmett *et al.*, 2013; Emmett *et al.*, 2014; Fitzgerald *et al.*, 2011; Gilmore-Bykovskyi, 2017; Gupta *et al.*, 2006; Jamieson *et al.*, 2016; Kable *et al.*, 2015; Kadushin and Kulys, 1994; Kuluski and McGeown, 2017; Levine, 2002; Macmillan, 2016; Mockford *et al.*, 2017; Poole et al., 2014; Rhynas *et al.*, 2018; Sewter, 2014; Shippen,

Young and Woods, 2011; Shyu, 2000; Telford, 2015). Two were case studies (Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017) and two reports (Boaden, 2016; Parliamentary Health Service Ombudsman, 2016). 26 articles were primary research studies. Nine articles originated from the UK, seven articles originated from Australia, four from the USA, one from Norway, one from Taiwan and one from Canada.

Following the re-run of the searches in 2022, four (Dabelko-Schoeny *et al.*, 2020; Sanatinia *et al.*, 2020; Sawan *et al*., 2021 Fry *et al.*, 2022) primary research articles regarding the experience of carers were identified as appropriate for inclusion and have been summarised and incorporated into the findings.

2.4.4 Discussion of study quality

All included studies were subjected to the CASP process allowing the author to assess their methodological quality. The purpose of a qualitative review is to support available evidence by amalgamating where findings have converged or diverged. The CASP process allowed opportunity to assess the quality of the papers and give greater weight to methodologically robust papers, whilst appreciating the contribution of other research paper findings. Papers were re-checked to ensure there was information regarding the experience of the discharge process specifically addressed within the body of the paper. The decision was taken not to discard any papers on the basis of quality, as within qualitative literature, quality criteria and applicability are highly disputed (Mays and Pope, 2000). The overall quality of the studies was inconsistent. In some included studies, there was a lack of transparency in relation to theoretical approach, method and analysis. For the patient synthesis, only seven of the primary research studies included involved people living with cognitive impairment directly (Norman, 2003; Huby *et al.*, 2004; Emmett *et al*., 2014; Dyrstad, Laugaland and Storm, 2015; Boaden, 2016; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b).

2.4.5 Key factors impacting on the discharge experience for people living with dementia (patient synthesis)

Table 5. Key factors impacting on the discharge process for patients.

Table 5
Theme 1: Patient undermined from taking part in discharge planning and decision making
Subtheme: Family members replacing patient in the discharge decision making process
Subtheme: Hospital system undermining ability of patient to have agency during the discharge process
Subtheme: Health and social care staff member's actions preventing patient involvement in the discharge process
Theme 2: Privileging of hospital requirements above patient centred care
Subtheme: Rushed discharge processes due to hospital requirements
Subtheme: Unsafe discharge practices due to hospital pressures
Theme 3: Absence of resource, policy, and governance in the hospital discharge process
Subtheme: Deficiency in availability of community services
Subtheme: Lack of adopted discharge policy initiatives alongside ad hoc discharge planning

The synthesis process occurred separately for the two groups: people living with dementia and carers. Three key themes and seven subthemes emerged from the meta- ethnography as the key factors impacting on the discharge experience of people living with dementia. The key themes included the patient being undermined from taking part in discharge planning and decision making, the privileging of hospital requirements above patient centred care and the absence of resource, policy, and governance in the hospital discharge process. Detail regarding the themes and subthemes is included in table 5.

Subthemes included: Family members replacing the patient in the discharge decision making process; the hospital system undermining the ability of patient to have agency during the discharge process; health and social care staff members actions preventing patient involvement in the discharge process; rushed discharge processes due to hospital requirements; unsafe discharge practices due to hospital pressures; deficiency in availability of community services and a lack of adopted discharge initiatives alongside ad hoc discharge planning.

2.4.5.1 Theme 1: Patient undermined from taking part in discharge planning and decision making.

Family members replacing patient in the discharge decision making process.

It was identified in several studies that relative's opinions were prioritised by health and social care professionals, over the opinions of people living with cognitive impairment (Kadushin and Kulys, 1994; Norman, 2003; Digby, Lee and Williams, 2018a; Rhynas *et al.*, 2018).

> *'Often during the early part of an admission, the views of family members predominated in comparison with an absent voice of the older person. In many of the case records, this dominant "voice" was maintained in records of formal meetings and conversations between relatives and staff.'*
>
> (Rhynas *et al*., 2018, p.6)

Rhynas *et al.* (2018) identified that relatives were often consulted about discharge decisions before patients, and that health and social care professionals were only inclined to listen to the views of people living with dementia if they corresponded with relative perspectives. Sometimes these decisions could be life changing for the patient. For example, Digby, Lee and Williams (2018a) identified that family members were applying for residential placements, at discharge for their relatives, and had not consulted them about this outcome.

> *'Bertha had been assessed by the neuropsychologist and deemed to be unable to make complex life decisions and therefore assessed as unsafe to return home. The team and the family had agreed that she needed permanent care. Not knowing what was going to happen but suspecting that*

> *residential care was being considered caused Bertha intense anxiety.'*
>
> (Digby, Lee and Williams, 2018a, p.75)

In accordance with this undermining of the patient, Kadushin and Kulys (1994) found that when patients had dementia, their involvement in the discharge process was often substituted for the involvement of their relatives by health and social care professionals (Emmett *et al.*, 2014). This can be problematic as it has been shown that family carers can have different discharge goals to patients (Emmett *et al.*, 2014; Poole *et al.*, 2014; Coleman and Roman, 2015).

> *'They shouldn't just look at the needs of the patient. They should look at the needs of the family ... if they are going to take the time to ask what are (the) goals of the patient ... then they should ask what do you need to have happen at home?'*
>
> (Coleman and Roman, 2015, p.15)

In contrast to the ways in which family involvement undermined patient involvement, some research (Dyrstad, Laugaland and Storm, 2015; Rhynas *et al.*, 2018) identified that adult children in particular could function as advocates for their relative and ensure that their opinion was represented during the hospital discharge process. Therefore, the involvement of relatives in the discharge process could have a positive or negative impact on the patient experience, dependent on whether the relative chose to act as an advocate or a replacement figure for the patient during decision making.

Hospital system undermining ability of patient to have agency during the discharge process.

The evidence identified that people living with dementia were often excluded from the discharge planning process, due to the nature of the hospital hierarchy which places the opinions of professionals above the opinions of lay members of the public, including carers (Kadushin and Kulys, 1994; Norman, 2003; Huby *et al.*, 2004; Emmett *et al.*, 2014; Telford, 2015; Gilmore-Bykovskyi, 2017; Digby, Lee and Williams, 2018a; Rhynas *et al.*, 2018). Findings identify that people living with cognitive impairment often feel powerless and unable to assert agency, during the hospital discharge process, particularly regarding identifying the discharge destination (Huby *et al*., 2004; Telford, 2015; Digby, Lee and Williams, 2018b; Rhynas et al., 2018).

> *'I asked her how she came in here. She said it was her leg. It would not bend. I asked her what she wanted. She wanted to go home. I asked her why she did not tell the doctor she wanted to go home. She said she could not tell them. 'It wouldna'e be rite'. Neither 'could she just tell them she was leaving'. I tried to ask her why not, but she could not explain. I asked if it was because they knew better, or because they had done things for her. She said it was because they had done things for her. I don't know if I put the idea to her and she just repeated it. I suggested that the nurse and doctors felt she would not be safe at home because she might fall like she had done earlier. She did not agree and said she felt she would be OK in her own home once she was settled. She told me that she had lost her husband 3 months ago, and that she was sure all this came from the shock. I asked if she had told anybody (in the hospital?) She said no, and that she could not tell them unless they asked her. I asked her if she knew what would happen now. She said she did not know.'*
>
> (Huby *et al*., 2004, p.119)

Kadushin and Kulys (1994) and Dyrstad, Laugaland and Storm (2015), identified that the paternalistic nature of the hospital system often excluded people living with dementia from discussions around discharge destination. Other researchers (Huby *et al.*, 2004) have suggested that the hospital system and process places people living with dementia in a passive position. For example, the nature of capacity assessments can undermine the agency of the patient with cognitive impairment (Norman, 2003; Poole *et al*., 2014; Digby, Lee and Williams, 2018a), as do the pre-eminence of formal assessments which exclude the subjective views of patients (Huby *et al.*, 2004). Emmett *et al.* (2014) found that capacity assessments were often conflated with best interest decisions, and that capacity assessments were often used to undermine patient involvement in their discharge. Poole *et al* (2014) also identified this.

> *'I think at the moment we've kind of got stuck with thinking, Right, what do we ultimately want for this person…. There's the patient, that's what we want for the person and how do we get there, rather than going through a*

> *nice routine process. Um ...... I suppose every patient who came on this ward, for instance, if their capacity just now was assessed, regardless of what the outcome's going to be, it would show that we're actually doing it routinely, rather than just when we need to do it, because we want to make a decision that the person's not going to like.'*
>
> (Poole *et al*., 2014, p.7)

Further to this, it has been suggested that the inherently opaque system of the hospital discharge process makes it difficult for people living with dementia to understand, let alone challenge, the process or its outcome (Huby *et al.*, 2004). Safety considerations and the language of risk are identified in several research findings as undermining the patient with cognitive impairment's ability to be involved in the hospital discharge process (Kadushin and Kulys, 1994; Norman, 2003; Emmett *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b; Rhynas *et al.*, 2018).

> *'It depends on what stage their dementia is really. As to whether we can discuss the options with them. Because most people want to go home.*
>
> *They don't realise that they won't be safe at home.'*
>
> (Norman, 2003, p.136)

Rhynas *et al.* (2018) argued that patients with cognitive impairment are often objectified due to the language of risk, and that patient safety is often prioritised over the patient's right to make decisions (Kadushin and Kulys, 1994; Emmett *et al.*, 2014; Hall *et al.*, 2020). Redwood, Eley and Gaughan (2016) identified that once it has been decided by a medical professional that it is too risky to discharge a patient home, it is very difficult for other healthcare professionals or patients to challenge that decision. Further to this, Huby *et al.* (2004) identified that narrow definitions of risk and set procedures, guided by formal assessments, often lead to the undermining and exclusion of patients from the discharge decision making process. Hall *et al.* (2020) identified that safety concerns were placed above the requirement for physiotherapy and rehabilitation for people living with dementia at discharge. Conversely, Schreiber, Powell and O'Dowd (2018) identified that there are occasions when health and social care professionals prioritise the patient's right to decide about going home over safety concerns.

> *'Physio: . . . we found that she had what we call an AMT score of five out of ten which means quite a large amount of confusion, unsure how much, what input she's going to remember from the previous day.*
>
> *Interviewer: So how much do you think Mrs B can be involved in making decisions about what happens to her when she leaves the hospital?*
>
> *Physio: She I mean she can be; she'll be involved in input. Obviously, we'll take inconsideration what she says but at the same time, we've got to remember that is she going to be safe going home with this or without this?'*
>
> (Huby *et al.*, 2004, p.124)

> *'On the other hand, if her discharge was delayed, Ms. X would have likely become more agitated. She might have required medications, possibly antipsychotics or benzodiazepines, to manage her agitation, which would have exposed her to their risks, up to and including death. Although there might have been some benefit to delaying her discharge to see if she would agree to another skilled nursing facility (snf) trial, the potential harms seemed to outweigh the benefits. Finally, to force her into a nursing home again seemed doomed to fail as she had already resisted both living with family and being discharged to a SNF. In weighing all of this information, the psychiatrist held Ms. X to a level 1 on Drane's sliding scale of decisional capacity 17 and determined that she had residence capacity to refuse a SNF and to return home.*'
>
> (Schreiber, Powell and O'Dowd, 2018, p.616)

Therefore, overcoming the notion of risk appears a significant barrier to people living with dementia having agency in the hospital discharge process, but it is not an impossible obstacle and can be overcome dependent on the actions of health and social care professionals.

Health and social care staff member's actions preventing patient involvement in the discharge process.

Health and social care staff actions were often identified as integral in the undermining of patients with cognitive impairment involvement in the discharge decision making process (Huby *et al.*, 2004; Norman, 2003; Telford, 2015; Rhynas *et al.*, 2018). Norman (2003) and Dyrstad, Laugaland and Storm (2015) recognised that patient perspectives were often left unacknowledged by health and social care staff.

> *Despite patients' objections and arguments of poor health, the decision to discharge patients was most often made by the professionals, with the patients being transferred to follow-up care in the municipality.*
>
> (Dyrstad, Laugaland and Storm, 2015, p.1702)

Further to this, some healthcare staff revealed, during interviews, that they believe people living with dementia are not able to make decisions in their own best interests during the hospital discharge process (Norman, 2003). The Department of Health and Social Care (2015) identified that prejudice amongst health and social care professionals prevented referral to services and care pathways connected to mobility. Huby *et al.* (2004) and Kadushin and Kulys (1994) found that health and social care professionals predominantly set discharge goals themselves, and a number of research findings identified that health and social care professionals regularly discussed discharge arrangements amongst themselves, without discussion with the patient with cognitive impairment (Norman, 2003; Huby *et al.*, 2004; Poole *et al.*, 2014; Dyrstad, Laugaland and Storm, 2015; Telford, 2015; Rhynas *et al.*, 2018). Further to this, Poole *et al.* (2014) found that health and social care professionals held the opinions and perspectives of colleagues in higher regard than patient opinions. This led to the undermining of the contribution of the patient to the discharge process.

> *'F: So, looking at maybe discharge plans, how much involvement do you think in your knowledge, do people with dementia have in their plans ... Is it possible to consult the person with dementia?*
>
> *S: Well with us, the only consultation they have is if we think oh bugger is this going to be EMI [Elderly Mentally Infirm unit] or EPH [elderly persons home], and then we get [name of Dr.] or one of his team to assess and they'll give us a "right he's going to need EMI" which they rarely say, they usually say "oh yes, EPH will be fine". And we say no. I mean that's usually the only input they get. Obviously if [Dr] says*

> *yes, they can't make their own decisions, fine, which invariably they don't which is quite reasonable really 'cos you're take away every single right they've got. Other than yes, I want to go home, that's about it.'*
>
> (Norman, 2003, p.139)

Although often unhappy with this, Huby *et al.* (2004) found during interviews with patients with cognitive impairment that they often felt uncomfortable challenging staff, even when excluded from decision making, as they felt they lacked the knowledge to challenge the hospital discharge process and didn't want to be seen as critical of individual staff members. A noted exception to this pattern was found by Telford (2015), who identified that health and social care staff were more open to collaboration with people living with dementia if the patient was to be discharged to a residential facility. Several other researchers also found that some health and social care professionals did support patient involvement in the discharge process (Poole *et al*., 2014; Dyrstad, Laugaland and Storm, 2015), although this was not the normative finding. However, overall research findings suggest that health and social care staff regularly undermined the participation of people living with dementia in the discharge planning process. This often led to great anxiety and distress for patients during the hospital discharge process (Norman, 2003; Huby *et al.*, 2004; Telford, 2015). Nevertheless, an important caveat to consider was identified in research by Huby *et al.* (2004) and Poole *et al.* (2014), where it was discussed that some patients living with cognitive impairment identified that they would rather not be included in the discharge process and preferred health and social care professionals to make key decisions.

> *Interviewer: And what does the term . . . have you heard the term 'patient participation'—it's kind of like a jargon word that is going about. What would 'patient participation' mean to you as a term?*
>
> *Respondent: 'Not a lot to be honest. I a'ways say let them that's qualified for ta (to) dae (do) it get on wi' it' (Man, 65, Stroke Unit)*
>
> (Huby *et al*., 2004, p.126)

2.4.5.2 Theme 2: Privileging of hospital requirements above patient centred care

Rushed discharge processes due to hospital requirements.

The privileging of hospital requirements above the needs of people living with dementia, during the hospital discharge process, was increasingly evident in relation to the need for hospital beds to be made available as soon as possible (Norman, 2003; Emmett *et al*., 2014; Dyrstad, Laugaland and Storm, 2015; Gilmore-Bykovskyi, 2017). People living with dementia were often reduced to their medical needs and diagnosis (Dyrstad, Laugaland and Storm, 2015; Telford, 2015; Kuluski and McGeown, 2017) and their non-medical requirements were ignored. Some research suggested that organisational hospital requirements were regularly prioritised above the needs of patients (Gilmore-Bykovskyi, 2017).

> *'To me it seems like sometimes the hospital just wants to dump the patients so to speak. Because they've got to get them out of there, and that's what they tell us all the time how they need beds, and they can't do anything for someone with dementia – they just need our long-term care. But then a lot of times it's completely different from what the social worker at the hospital tells our social worker."*
>
> (Gilmore-Bykovskyi, 2017, p.873)

Tight hospital schedules led to limited time for health care professionals to discuss discharge options with people living with dementia (Dyrstad, Laugaland and Storm, 2015). Due to the pressure to discharge people living with dementia, following the resolution of their medical conditions, it was found that some patients were discharged prematurely (Parliamentary Health Service Ombudsman, 2016) and that these premature discharges could lead to poor and unsafe discharge experiences for the patient (Gilmore-Bykovskyi, 2017). Further to this, Dyrstad, Laugaland and Storm (2015) identified that rushed discharge could often leave the patient struggling to remember and understand information provided on the day of discharge.

> *One son said (to the researcher on the phone): 'The discharge came very soon. They could have called a day*

> *before discharge'. The next of kin also picked up medications from the pharmacy; family members were sometimes observed to drive the discharged patient from the hospital to the nursing home, as they did not want the patient to take a taxi. According to one son of an 87-year-old woman with malnutrition, 'Cognitively impaired or not makes no difference. To include family is important. The older patients often do not remember and cannot answer questions about their own health conditions'.*
>
> (Dyrstad, Laugaland and Storm, 2015, p.1702)

Unsafe discharge practices due to hospital pressures

Unsafe discharges were identified in several reports and highlighted by case studies of individual experience for people living with dementia (Kable *et al.*, 2015). Cumbler, Carter and Kutner (2008) identified that pressure to free up bed space could lead to patients being discharged over a weekend, and this could be hazardous as services and staff usually available are often absent over a weekend period. Further to this, the Parliamentary Health Service Ombudsman report (2016) found multiple cases of people living with dementia being discharged overnight. This was identified as being a dangerous practice which could lead to an extremely poor discharge experience for the patient with cognitive impairment.

> *'Mrs K was transferred to the acute medical unit to wait for an ambulance. An ambulance was booked at 8.48pm; Mrs K's medical notes showed this was before she had expressed her preference to go home. It arrived at 11pm. Although the hospital had been unable to reach Mrs K's son to let him know that they planned to discharge his mother, it let Mrs K go home.*
>
> *The following morning Mrs K's daughter, Mrs G, visited her at home. She found that her mother had been left with no food, drink and bedding, unable to care for herself or get to the toilet.'*
>
> *Relative: 'Surely when family members have made their concerns 100% clear and a vulnerable, virtually immobile 93-year-old is sent home alone, something is very wrong somewhere.'*
>
> (Parliamentary Health Service Ombudsman, 2016, p.19)

2.4.5.3 Theme 3: Absence of resource, policy, and governance in the hospital discharge process

Deficiency in availability of community services

Huby *et al.* (2004), Emmett *et al.* (2014), Kable *et al*. (2015), and Kaiser and Kaiser (2017), identified that a deficiency in the services available, on discharge to the community, resulted in discharge destination being based on availability and not suitability. This lack of availability led to people living with dementia experiencing extended delays in the discharge process (Parliamentary Health Service Ombudsman, 2016). Telford (2015) and Kable *et al.* (2015) further identified that delays in discharge were often as a result of awaiting community placements, and that delayed discharge could be due to poor co-ordination across services in the community (Parliamentary Health Service Ombudsman, 2016).

> *'...a long waiting list for access to community physio, . . . day hospital, could be weeks. . . we've had people . . . waiting for up to 2 years ...if the service hasn't come after 30 days, they drop off that list and they're not in the system (DP group).'*
>
> (Kable *et al*., 2015, p.5)

Lack of adopted discharge policy initiatives alongside ad hoc discharge planning.

A number of studies identified that patients were often experiencing poor and ad hoc discharge planning, leading to discharge without a formal discharge plan, or with an untailored and inappropriate plan, resulting in anxiety for the patient during the discharge period (Bauer, Fitzgerald and Koch, 2011; Kable *et al*., 2015; Boaden, 2016; Jamieson *et al*., 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017).

> *'If... you could sit down (with each patient) and say this is why you were here, this is the plan when you leave, but it actually happens very rarely (JMO group).*
>
> (Kable *et al*., 2015, p.6)

Discharge summaries could be insufficient with no attention paid to social or dementia related needs, but only medical requirements (Kable *et al.*, 2015). One comprehensive report (Parliamentary Health Service Ombudsman, 2016) identified that hospitals were at times omitting to implement capacity assessments, leading to instances of deprivation of liberty for patients. There was also a noted lack of safeguarding occurring in many hospital discharge processes for people living with dementia (Cumbler, Carter and Kutner, 2008; Boaden, 2016; Jamieson *et al.*, 2016; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016).

> ‘*After a 2 week stay, the hospital decided to discharge him on the Thursday before the August Bank holiday weekend, when support was not available until the next Tuesday because of the holiday. It was at home that the wife discovered that, as well as being incapacitated with a broken hip, her husband was doubly incontinent – she couldn’t cope. After a day the out-of-hours doctor advised her to take her husband to A&E. She had to leave him there to look after her autistic son. The husband called to say he was being discharged. The wife refused to bring him home because he couldn’t walk, and he was admitted onto a ward.’*
>
> (Macmillan, 2016, p.194)

Multiple reports revealed that people living with dementia are at risk of being discharged to their home address with no heating, food, care packages, family support or access to toilet facilities (Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016). Bauer, Fitzgerald and Koch (2011) reported an instance of a patient being discharged home with an injury which had gone unnoticed, suggesting a worrying absence of people living with dementia being safeguarded at discharge. Further absences of safeguarding are evident, specifically around medication provision at the point of discharge (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kable *et al*., 2015; Deeks *et al.*, 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017).

> *‘At 5 pm with 3 pages of discharge medications, new initiations of warfarin. they are actually really unsafe discharges. (#4 hospital pharmacist)’*
>
> (Deeks *et al*., 2016, p.453)

Numerous studies found that people living with dementia were discharged home or to residential facilities without medication, or with the wrong medication (Cumbler, Carter and Kutner, 2008; Kaiser and Kaiser, 2017). Deeks *et al.* (2016) found that there was often a lack of information around medication schedules, or changes implemented in the hospital context, communicated to care providers and community services at the point of discharge. This was found to lead to multiple medication errors during the transitionary discharge process (Kaiser and Varghese, 2014). It was identified that people living with dementia were often discharged from hospital without the correct assessments being completed and without social service involvement (Boaden, 2016; Parliamentary Health Service Ombudsman, 2016). Another issue caused by ad hoc discharge planning was the prevalence of long waiting periods for transport home or to residential placements. Telford (2015) identified that multiple patients with cognitive impairment experienced the day of discharge itself as a taxing experience, due to being delayed, due to a dearth of available discharge transport.

> *Frederick: Of course, she was getting distressed. I was getting angry.*
>
> *Clive: [It was a] bit stressful, because [we were] waiting a long time for an ambulance … we waited nearly the whole day for her [my wife] to arrive.*
>
> (Telford, 2015, p.111)

This synthesis has identified the experiences of people living with dementia of the hospital discharge process. In the next section, the synthesis of carer experiences will be presented, beginning with the key factors that emerged from the meta-ethnography.

2.4.6 Key Factors impacting on the discharge experience for carers of people living with dementia (carer synthesis)

Table 6. Key factors impacting on the discharge experience for carers of people living with dementia (carer synthesis)

Table 6
Theme 1: Carer experience of being included in the discharge process.
Subtheme: Experience of being included in the discharge planning process (positive aspects)
Subtheme: Experience of being included in the discharge planning process (negative aspects)
Theme 2: Experience of being excluded from the discharge planning process
Subtheme: Not being treated as an expert in the care of the person living with dementia
Subtheme: Recipient of ineffective communication
Theme 3: Requirement for further robust support during discharge process
Subtheme: Unmet need for support for carer navigating the discharge process

The synthesis of the experience of the hospital discharge process for carers revealed three main themes. These included: **the experience of being included in the discharge process; being excluded from the process; and a requirement for further robust support**. Five subthemes were identified including: the positive and negative aspects of being included in the discharge process; not being treated as an expert in the care of the person living with dementia; being the recipient of ineffective communication, and the unmet need for support for the carer navigating community services. Further information relating to the themes and subthemes is included in table 6.

2.4.6.1 Theme 1: Carer experience of being included in the discharge process.

Experience of being included in the discharge planning process (positive aspects)

For carers, the hospital discharge can be experienced as an empowering process when it occurs in partnership with health and social care professionals (Cox, 1996). Good communication between family carers and professionals can enable a constructive discharge experience and ensure positive discharge outcomes for both the patient and their family (Gupta *et al.*, 2006; Fitzgerald *et al.*, 2011; Emmett *et al.*, 2014;).

> *'Mrs Baker was 88 and prior to her admission to hospital lived in her own bungalow with the help of professional carers and her family who lived locally. She was admitted to hospital with a UTI and was assessed as being on the borderline of lacking capacity to decide where she should live. The professional decision to discharge Mrs Baker home was facilitated in no small part by her family's tenacious and persistent questioning of hospital professionals and their familiarity with hospital processes.'*
>
> (Emmett *et al*., 2014, p.314)

> *'Well, there was quite a bit of information given to me and a lot of the services that I could expect after she came back home, that was all arranged by the welfare people, [which began] during the whole four weeks. I remember the relevant people in the welfare department [saw me] and they would give me some information. And a couple of times I was actually in an office, invited to talk with someone in the office, and quite a bit of information was given to me. I'm quite happy with what was provided. [John, husband].*
>
> (Fitzgerald *et al*., 2011, p.367)

Ensuring productive relationships with key professionals, such as pharmacists (Coleman and Roman, 2015), involving family members with an understanding of the health and social care system (Emmett *et al.*, 2014) and the presence of collaborative partnership working within the health and social care professional multi-disciplinary team (Jamieson *et al.*, 2016) have been identified as integral to a positive and timely discharge experience (Gupta *et al.*, 2006). Further to this, continuity in the professionals involved in the discharge process was identified as crucial to ensuring a positive experience for carers (Rhynas *et al.*, 2018).

Formal discharge planning meetings allowing carers an opportunity to share their concerns, opinions and granting agency for involvement in decision making, was identified by several studies as integral to enabling a positive hospital discharge experience (Cox, 1996; Gupta *et al*., 2006; Rhynas *et al.*, 2018). The plan to discharge into a care home setting also appeared to improve collaboration between professionals and carers (Cox, 1996; Telford, 2015) along with the presence of a formal 'title' for the carer, such as holding power of attorney (Coleman and Roman, 2015).

> *'Several family carers suggested that family titles (i.e., daughter or spouse) seemed to garner more respect from health professionals. Others made reference to the importance of being identified in a functional role such as healthcare power of attorney.*'
>
> (Coleman and Roman, 2015, p.18)

However, several studies identified that good practice appears to be linked to local champions, local networks and individual good practice (Cooper and Deeks, 2012; Deeks *et al.*, 2016) rather than policy or process led systems. The good clinical practice enabled by positive communication, settings which enable shared decision making and inter-professional working practices, appears relatively infrequently in the included studies, in comparison to the focus on the negative experiences of carers being excluded from the discharge planning process, or the negative experiences connected with being involved in the hospital discharge.

Experience of being included in the discharge planning process (negative aspects)

Although carer involvement in the discharge planning process can be a positive experience, a range of negative aspects to involvement were identified in the studies. Being involved in the discharge planning process has been identified as potentially having a negative impact on a carer's mental health (Macmillan, 2016). A number of the included studies identified that challenges encountered as part of the discharge process caused anxiety, exhaustion and stress, and significant disappointment at the mismatch between their expectations, and the reality of the discharge process (Cox, 1996; Jamieson *et al.*, 2016; Sanatinia *et al.*, 2020).

> *'I can't handle this anymore; I'm absolutely buggered from no sleep at all, all night*.' (Partner)
>
> (Jamieson *et al.*, 2016, p.862)

Carers appear to experience stress or frustration in relation to; interactions with health and social care professionals (Telford, 2015); worries in relation to finance and funding around care packages (Mockford *et al.*, 2017); poor service delivery (Mockford *et al.*, 2017); feeling judged in relation to their caring abilities by professionals (Jamieson *et al.*, 2016) and poor documentation (Kable *et al.*, 2015), with the day of discharge being acknowledged as a particularly anxious period (Telford, 2015).

> *'Some carers worried about how to pay for the cost of social care at home in the future.'*
>
> (Mockford *et al.*, 2017, p.502)

Jamieson *et al.* (2016) identified that carers often experience exhaustion at the lack of co-ordination within the hospital discharge process. In answer to this, Coleman and Roman (2015) found that carers try to take on the coordinating role themselves and find navigating this both challenging and frustrating. A significant source of emotional conflict for carers is in relation to care home placement on discharge for the patient. Multiple studies identified how conflicted carers feel in relation to hospital discharge to care home locations (Kadushin and Kulys, 1994; Cox, 1996; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). Many carers experience feelings of guilt, grief and depression (Cox, 1996; Bloomer *et al*, 2016) and will struggle to ensure that their relative is discharged home, even if this is potentially inappropriate, particularly if the person living with dementia is a parent (Bloomer *et al*, 2016; Rhynas *et al.*, 2018). Being involved in the decision to admit the person living with dementia to a care home was identified also have a negative impact on wider family relationships for the carer (Bloomer *et al*, 2016) compounding the impact on their mental health.

> *'It's a different thing when Mum was living with us. He just didn't handle things, and I was between the devil and the deep. I didn't want to - Mum needed the care. I felt that she wasn't ready to go into a nursing home at that stage, and yes, it was awful. It affected me very badly.'*
>
> (Bloomer *et al*, 2016, p.907)

2.4.6.2 Theme 2: Carer experience of being excluded from the discharge planning process.

The included studies identified that being excluded from the discharge planning process was a central facet to the hospital discharge experience for carers, with a minority of hospitals having a system for including relatives formally in the process (Emmett *et al*., 2014; Dyrstad, Laugaland and Storm, 2015). The experience of being excluded can be broadly divided into two aspects: not being treated as an expert in patient care; and being the recipient of ineffective communication.

Not treated as an expert in the care of the person living with dementia

Several studies identified that not being treated as an expert in patient care was central to many carers hospital discharge experience (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016). Habitually, carers are not invited to discharge planning meetings (Dyrstad, Laugaland and Storm, 2015), and even if invited they are not given warning about the topics to be discussed, or adequate time to think through the decisions to be made (Emmett *et al.*, 2014). Carers identified that they do not feel involved in decision making (Mockford *et al.*, 2017) and do not feel that the discharge process itself is collaborative (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016).

> *'Sometimes it was a bit frustrating to try and find who's looking after her and where is that person... unless you actually caught somebody at the bedside, we didn't have a lot of information. (Daughter)*
>
> *I would have liked to have one person I could go to. They [the hospital] didn't have anybody that I could just say well, I'll ask the question of this person... I just didn't get the communication happening.... (Husband)*
>
> (Bauer *et al.*, 2011, p.320*)*

Carers argued that they felt ‘unheard’ (Coleman and Roman, 2015; Telford, 2015) and that their unique knowledge of the patient was not sought by health and social care staff. Carers identified feeling disempowered by the health and social care team and being unaware of the actions and decisions occurring in relation to the discharge process (Bloomer *et al*, 2016). Emmett *et al.* (2014) identified that social care professionals referred to written medical notes to aid decision making and did not elicit the opinions of carers.

> *‘And even the second time, … even then it was still negative, you know; ‘Well I’m concerned about such and-such, and such-and-such’; no interest in the whole patient; it’s just, I’ve got this information from the documentation and I’m going to read it out for you.’*
>
> (Poole *et al*., 2014, p.10)

Similarly, Coleman and Roman (2015) found that discharge goals were set by health and social care professionals and not by carers. Further to this Emmett *et al.* (2014), found that medical knowledge was often used to undermine the opinion and perspective of the carer. Being involved in discharge meetings was, at times, referred to by professionals to, ‘manage carer expectations.’ The implications of this are not indicative of a collaborative discharge process (Sanatinia *et al.*, 2020).

Predictably, the exclusion of carers from the decision-making process meant that multiple studies identified that health and social care professionals make discharge decisions amongst the multi-disciplinary team and community services only (Dyrstad, Laugaland and Storm, 2015; Telford, 2015). Where carers were involved in discharge planning and decision making, it was in a superficial manner (Kadushin and Kulys, 1994). An example was identified in Kuluski and McGeown (2017), where carers were able to choose the long-term placement destination for their relative but were unable to have any influence over when or how the placement would begin. Carers identified feeling powerless (Telford, 2015) or undermined (Emmett *et al.*, 2014) in their interactions with health and social care professionals and struggled to influence discharge decisions (Emmett *et al.*, 2014). The absence of a formal discharge plan exacerbated the feelings of being unable to have agency in the discharge process (Fitzgerald *et al.*, 2011).

> *'Yeah. Well, they seemed to be very pushy in, you know, getting him out of there, out of the [hospital]. I guess they needed the beds or something. And he [her son] says, "Mom, I think we've been railroaded." We didn't like the way it was going. They were suggesting that he come home. And we said no because I don't know if I could cope with that and I think it would have been too much for me.'*
>
> (Kuluski and McGeown, 2017, p.5)

This experience of exclusion led to many carers reporting a difficult relationship with health and social care professionals (Bauer, Fitzgerald and Koch, 2011). Professionals not valuing carers as a resource, and the inherent power imbalance within interactions (Telford, 2015), created distrust within the therapeutic relationship. Carers reported feeling frustration and resentment towards professionals involved in the discharge process, particularly when professionals displayed a lack of training, or knowledge of the needs of people living with dementia (Mockford *et al.*, 2017).

> *'Dealing with Mum's incontinence . . . I said to them about taking her to the toilet every so often and I proved it to them on the home visit . . . The Occupational Therapist said ''Do you want to go to the toilet Anne?'' and I said, ''No, no, no, no, you're not listening!'' I said, ''just take her there!'' So I steered her there. I got them to do it for about three more times during the day—''Oh this is working—we've got no wets [incontinence].'' The next day I go back and it's all reversed!' (Daughter)*
>
> (Bauer Fitzgerald and Koch., 2011, p.12)

Recipient of ineffective communication

One of the universal features of the carer experience, identified across multiple studies, was being the recipient of ineffective communication (Bauer *et al.*, 2011; Fitzgerald *et al.*, 2011; Emmett *et al.*, 2014 Sewter, 2014; Telford, 2015; Bloomer *et al*, 2016; Boaden, 2016; Deeks *et al.*, 2016; Mockford *et al.*, 2017). This was in relation to both communication between health and social care professionals and carers (Bauer, Fitzgerald and Koch, 2011; Fitzgerald *et al.*, 2011), and between organisations and professionals themselves (Sewter, 2014). Carers experienced ineffective communication in multiple settings (Deeks *et al.*, 2016) and in relation to a range of services, processes, and care needs (Mockford *et al.*, 2017). Carers identified that there was a lack of clear hospital policies in relation to communication with family carers (Bauer *et al.*, 2011), and experienced occasions where information was only communicated to the patient living with dementia (Dyrstad, Laugaland and Storm, 2015). This ineffective communication was identified as being culpable for the breakdown of service provision (Bauer, Fitzgerald and Koch, 2011).

> '*I would like just to be kept informed about what's happening. Certainly, kept informed if there are any ideas, that maybe she won't be able to continue the kind of care that she's been getting— those sort of things. You need to know what's going on.' (Daughter)*
>
> (Bauer, Fitzgerald and Koch, 2011, p.11).

Carers identified the absence of effective signposting (Bauer *et al.*, 2011; Emmett *et al.*, 2013; Emmett *et al.*, 2014) as a problem. Multiple studies highlighted that obtaining information was far from a straightforward process for carers, who found it difficult identifying who to approach within the health and social care team, for information about their relative (Bauer, Fitzgerald and Koch, 2011). Many studies identified that only when carers were particularly pro-active in ringing the ward, and approaching health and social care team members, did they believe they had experienced effective communication (Dyrstad, Laugaland and Storm, 2015; Kaiser and Kaiser, 2017).

Ineffective communication as a problem presented itself throughout the discharge process. Carers were often not provided with clinical information at the point of discharge (Bauer *et al.*, 2011; Emmett et al., 2013; Emmett *et al.*, 2014) including the results of diagnostic tests (Kaiser and Kaiser, 2017). Carers were often not provided with information about the discharge day or time, leading to potentially dangerous scenarios (Boaden, 2016; Macmillan, 2016).

An example of a common scenario was identified in Bauer, Fitzgerald and Koch (2011, p. 1)

> *'They were saying, 'we're planning to put her in a taxi and send her home.'' And I said, ''You can't do that, she's got dementia. She'll be really disoriented, and she hasn't even got a house key.'*

Sometimes carers identified relatives being discharged at the weekend without warning (Cumbler, Carter and Kutner, 2008), or being given very short notice for a same day discharge (Dyrstad, Laugaland and Storm, 2015; Jamieson *et al.*, 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017). The importance of timely discharge planning was highlighted by a number of carers (Fitzgerald *et al.*, 2011; Shippen, Young and Woods, 2011) as central to ensure a safe and effective discharge process. It was also highlighted that being physically present on the ward ensured more robust discharge planning and safeguarding (Fry *et al.*, 2022).

Insufficient information and advice in relation to medication administration was reported by many carers across the studies (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017; Sawan *et al.*, 2021). Not having changes to medication regimes explained (Deeks *et al*., 2016) or not being provided with medication at the point of discharge (Cumbler, Carter and Kutner, 2008), were highlighted as problematic. Coleman and Roman (2015) and Sawan *et al.* (2021) argued that carers often feel overwhelmed by the medication administration schedule. Kable *et al.* (2015) found that both the dosage and the administration timetable were not clearly explained to carers, leading to confusion and anxiety.

> '*She [care receiver] is taking too many kinds of medications. This morning, I planned to prepare all the medications for this week and put them into separate bags according to the meals they are taken with, but I could not do it because it is so confusing,'*
>
> (Shyu, 2000, p.622).

Further to this, Deeks *et al.* (2016) identified that an absence of sufficient communication with community pharmacies, regarding medication changes, also caused difficulties for carers post-discharge in the community. There was also insufficient communication for carers, both before and during the discharge process, in relation to caregiving skills and abilities (Shyu, 2000;

Levine, 2002; Bauer, Fitzgerald and Koch, 2011). Several studies highlighted that despite carers expressing a desire to experience training in relation to carer skills before discharge (Levine, 2002), health and social care staff are neither teaching these skills (Kaiser and Kaiser, 2017), nor assessing the carer's ability to provide care before discharge (Parliamentary Health Service Ombudsman, 2016).

> *'They described the lack of training in complex medical equipment that they were responsible for operating at home. What training was provided was perfunctory and dismissive of their fears.'*
>
> (Levine, 2002, p.175)

This often led to carers feeling unprepared for their role as carers following the discharge process (Coleman and Roman, 2015). In addition to feeling that they were unprepared for their carer role, carers also reported not being informed about available community support services or how to access them (Mockford, 2015; Shyu, 2000). Carers identified that there was a lack of co-ordination between hospitals and community services and care providers and requested that it would be beneficial for ward staff to arrange community services before their relatives exit the hospital setting (Shyu, 2000).

The prevalence of poor communication experiences is unfortunate, as several studies (Shippen, Young and Woods, 2011; Gupta *et al.*, 2006) found that carers felt empowered and supported during the discharge process by experiencing good communication. Moreover, a formalized setting where discussions could take place between the carer and health and social care team, and formulate a formal discharge plan, enabled the carer to manage the discharge process more effectively than where no formal process is available (Gupta *et al.*, 2006).

2.4.6.3 Theme 3: Requirement for further robust support during discharge process

Unmet need for support for carer navigating the discharge process.

Carers reported a deficiency in the support available from health and social care services and individuals, during the hospital discharge process (Bauer, Fitzgerald and Koch, 2011; Coleman and Roman, 2015; Kuluski and McGeown, 2017). Numerous studies identified that while there is support available for carers, it does not appear to be woven into the fabric of the discharge process itself, and carers are often unaware of its existence (Coleman and Roman, 2015; Kuluski and McGeown, 2017). Carers felt that there was a deficiency in the emotional support available (Kadushin and Kulys, 1994; Shyu, 2000; Jamieson *et al.*, 2016) and identified that a service to support their mental health would be helpful (Shyu, 2000). The emotional struggle many carers experienced was evident.

> *'I am under a lot of pressure, long-term pressure. I need someone to talk to, to dump my garbage and an outlet for my emotional pressure.'*
>
> (Shyu, 2000, p.623)

Carers reported experiencing the discharge process as rushed, with little time to absorb new information or being supported to contribute to decision making (Kaiser and Kaiser, 2017; Dabelko-Schoeny *et al.*, 2020). Several studies identified that this rushed process often led to medication errors (Kaiser and Varghese, 2014; Coleman and Roman, 2015) and the discharge plan being dictated to carers, rather than being developed in a collaborative manner (Telford, 2015).

Carers identified that their needs were often overlooked in favour of the patients' needs (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016) or the requirements of the hospital system (Parliamentary Health Service Ombudsman, 2016; Kuluski and McGeown, 2017).

> *'I'm thinking ''What am I going to do? How am I going to manage this?'' Well really, getting the right information and obviously when - see, they're only working on him, and they got to work on the family'.*

(Bloomer *et al*, 2016, p. 310)

Carers were not asked whether they felt confident to continue in a caring role (Bloomer *et al*, 2016), and some carers (Kuluski and McGeown, 2017) reported feeling pressured to facilitate the return home of the patient living with dementia, before a long-term care plan was in place, to ease pressure on the ward. One carer reported begging ward staff not to discharge her husband, as she felt she could not manage his care requirements (Parliamentary Health Service Ombudsman, 2016). Further to this, the carer reported that she was not assessed in relation to her ability to provide care or whether she owned the correct equipment to provide the necessary care to her husband (Parliamentary Health Service Ombudsman, 2016). This failure to consider the needs of carers was identified as having a negative impact on the mental health of the carer themselves (Bloomer *et al*, 2016).

Complexity of navigating community services

Carers consistently reported issues relating to the complexity of navigating community services both during and after the hospital discharge process (Parliamentary Health Service Ombudsman, 2016). Carers reported this was made more difficult by the lack of co-ordination between health and social care systems (Parliamentary Health Service Ombudsman, 2016), including a dearth of information sharing (Shippen, Young and Woods, 2011) and communication (Gilmore-Bykovskyi, 2017). This is further exacerbated by local authority boundaries adding to confusion around which services are available to carers (Jamieson *et al.*, 2016).

Many carers reported a delay in services starting in the community, leaving carers to try and manage patient care needs alone upon discharge (Jamieson *et al.*, 2016). Others reported either a lack of affordable and available resources (Emmett *et al.*, 2013; Kable *et al.*, 2015) or inconsistent access to both GP and community services (Kable *et al.*, 2015; Jamieson *et al.*, 2016). Across the studies, it was often acknowledged that the services and resources available in the community did not meet the needs of carers (Bauer, Fitzgerald and Koch, 2011) and this entailed that discharge plans were often inadequate (Mockford *et al.*, 2017).

> *...a long waiting list for access to community physio, . . . day hospital, could be weeks. . . we've had people . . . waiting for up to 2 years ...if the service hasn't come after 30 days, they drop off that list and they're not in the system. (DP group)*
>
> (Kable *et al*., 2015, p.6)

Inflexible care arrangements via care agencies, and last-minute changes in care service availability, were identified as causing a lot of stress for individual carers (Mockford *et al*., 2017). Further to this, Mockford *et al*. (2017) identified that inexperienced care workers, and poor-quality interactions with care agencies, exacerbated the problems experienced by carers. Many reported experiencing fragmented services and identified significant gaps in the provision of community care support, leading to further experiences of emotional distress for the carer (Jamieson *et al.*, 2016).

When services aimed at both individuals living with dementia and their carers were available, gaining access was often challenging (Kable *et al.*, 2015; Jamieson *et al*., 2016). Long waiting periods were experienced for vital physical and emotional support services, including respite (Kable *et al.*, 2015), with carers expected to fill in the gap in care provision. Sometimes access to GPs was limited, (Deeks *et al.*, 2016) as was access to support groups and networks. This is particularly problematic as community carer networks and support groups have demonstrated the ability to provide emotional, and informational support, for carers following the discharge process (Jamieson *et al.*, 2016).

> *'Being able to compare notes and talk about what services are available, the other members of the group often know about things... support that I don't. It's good to share; if you didn't laugh sometimes, you would just cry. Alzheimer's is a cruel disease. (Daughter 4)*
>
> (Jamieson *et al.*, 2016, p.901).

Many of the carers identified that the reason they found navigating community services highly challenging was due to an undeveloped or even absent discharge planning process (Bauer, Fitzgerald and Koch, 2011; Sewter, 2014; Jamieson *et al.*, 2016). Carers identified there was often no formal discharge plan available (Bauer *et al.*, 2011), due to the pressure to discharge from the hospital into the community quickly (Gilmore-Bykovskyi, 2017). This absence of a discharge plan meant that there was no road map available to guide carers, the presence of which may have enabled a more effective discharge process (Shippen, Young and Woods, 2011; Mockford *et al.*, 2017).

> *'Well, it would be nice if you were told . . . have advanced notice, so you can plan to do things. It would be good to have at least one or two people you knew you could talk to each time to get feedback on whether or not she could come home or not. Obviously, one would like to be told . . . so that you could do the right thing.' (Daughter)*
>
> (Bauer, Fitzgerald and Koch, 2011, p.13)

A few studies identified that a mutually agreed, formal discharge plan (Mockford *et al.*, 2017) with shared, identified goals (Shippen, Young and Woods, 2011) led to a positive discharge experience for carers. Planning in a timely manner for discharge, with carers aware of the discharge timeline, also facilitated a positive experience, and opportunity for carers to ask questions and make their own requirements known (Gupta *et al.*, 2006). Moreover, a discharge communication clinic which facilitated discussion, between health and social care services and carers, and organized formal meetings, was shown to enhance the hospital discharge experience immensely (Gupta *et al.*, 2006).

2.5 Discussion of patient and carer synthesis

The findings of the patient synthesis reveal that many people living with dementia have a negative experience of the hospital discharge process. This is due to being undermined from taking part in discharge planning and decision making, due to the actions of family members, health and social care professionals and the hospital system. Considerations of risk particularly undermine the agency of people living with dementia. Further to this, it is evident that hospital requirements are often privileged above person centred care, leading to rushed and unsafe discharge practices. The potential absence of resource, policy and governance in the hospital discharge process is often problematic and has a negative impact on the patient experience. A lack of community resources and formal discharge policies and plans are shown to lead to negative outcomes for the patient, particularly around safeguarding.

Carer experiences of the discharge process have many similarities with the experiences of people living with dementia, but there are also significant differences evident. Carers experience deficiencies in communication and exclusion from the discharge planning process, poor discharge planning, and rushed discharge processes due to hospital considerations being prioritised above the needs of people living with dementia. However, carers are often responsible for navigating community services, and the key processes of the discharge itself, on behalf of the person living with dementia. Carers are also placed into a secondary position within the discharge process, and report frequently finding their needs overlooked or undermined during discharge planning. The experience of carers and people living with dementia of the discharge process may be similar, but their requirements for support are different resulting from their different roles within the process. Jamieson *et al.* (2016) has argued for a policy requirement to substantively support carers, alongside people living with dementia, to ensure that they receive the correct training and support before the discharge process is executed. A requirement for a shift in focus to ensure a discharge process more aware of the carer experience emerges from a few of the studies, and a need for a formalised discharge process (Fitzgerald *et al.*, 2011; Mockford *et al.*, 2017).

A significant proportion of the literature addressing the hospital discharge experience for people living with cognitive impairment, focuses on their involvement, or lack of involvement in the discharge planning process (Kadushin and Kulys, 1994; Huby et al., 2004; Dyrstad, Laugaland and Storm, 2015). This is also true of the carer synthesis (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). This prevalence is reflected in the themes identified during the meta- ethnography process and reveals the key focus of much of the research previously undertaken in this area.

Additionally, the research papers included in the review often focus upon negative experiences described by participants (Norman, 2003; Telford, 2015). This may be due to selection bias as many of the papers have a focus on improving the hospital discharge process and may be actively aiming to identify areas for improvement, rather than examples of good practice. The synthesis identified that there is limited evidence available about the factors that ensure a positive discharge experience for the patient living with dementia. This has also been identified by Shippen, Young and Woods (2011). This omission must be addressed in future research to ensure that the experience of people living with dementia is available to policy makers, medical and nursing staff, and to guide everyday ward practice and evidence-based discharge policies.

It was identified that a greater proportion of the research available addressing the topic of hospital discharge is focused on the carer experience (Bauer *et al.*, 2011; Coleman and Roman, 2015; Jamieson *et al.*, 2016; Kuluski and McGeown, 2017). This may be due to the difficulties, surrounding capacity and informed consent, inherent in research involving people living with cognitive impairment (Kuluski and McGeown, 2017). However, most people living with cognitive impairment are capable of involvement in research studies, if the provisions of the Mental Capacity Act (Department of Health, 2007), or national equivalent are adhered to. The absence of opinion from people living with dementia from studies exploring hospital discharge is concerning. It suggests that their experience and views are underrepresented, in favour of the views of carers and family members, who may have different perspectives and needs during the discharge procedure. Further research which includes people living with dementia is required to address this gap in the evidence base and enable nursing and medical staff to develop a better understanding of the needs of people living with dementia during the discharge process. This was a priority of this research project but was not possible during the empirical data collection period during the pandemic.

An interesting juxtaposition lies in the contrast between the significant focus on risk assessments during the discharge planning process (Kadushin and Kulys, 1994; Emmett *et al.*, 2014; Redwood, Eley and Gaughan, 2016; Digby, Lee and Williams, 2018b; Rhynas *et al.*, 2018), and an identifiable lack of safeguarding apparent during the discharge process (Cumbler, Carter and Kutner, 2008; Kaiser and

Varghese, 2014; Kable *et al.*, 2015; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). The two processes are vital to patient safety but appear to be given unequal attention during the discharge process. This contrast may highlight that once a patient leaves the hospital setting, health and social care professionals feel that they are no longer their responsibility, but the responsibility of a community-based service. As the hospital discharge progression should be viewed as one ongoing process (Redwood, Eley and Gaughan, 2016), this perspective should be challenged to ensure that the patients view of the discharge process is privileged during the hospital discharge process. Furthermore, clinicians must ensure that safeguarding concerns are sufficiently addressed before the patient is discharged. The adoption of a more person-centred approach to the discharge process may facilitate this, as this approach has been shown to be successful in other ward-based practice areas (Clissett *et al*., 2013). Further research into this topic is required. During the updated search in April 2022, one of the findings emerging from the research conducted by Fry *et al.* (2022) was the importance of the physical presence of a carer, during the discharge process, to safeguard the wellbeing of the person living with dementia. This finding has significant meaning in the post- pandemic climate, due to the physical absence of carers during the discharge process in the pandemic context.

The exclusion of the patient and the carer from decision making processes (Norman, 2003; Emmett et al., 2014; Telford, 2015; Rhynas *et al.*, 2018) must be challenged to support the patient to take part in discharge planning. This is vital to preventing patients being undermined, and omitted from the process, through the paternalism of the hospital system, or being replaced by relative involvement. This is especially important as the synthesis revealed that relative and carer involvement can have a positive or negative impact on patient experience (Emmett *et al*., 2014; Coleman and Roman, 2015; Dyrstad, Laugaland and Storm, 2015; Rhynas *et al.*, 2018). Clinical staff must be supported in this by hospital policy and procedures that support patient agency. However, it was revealed that some patients do not want to be involved in the decision-making process. This contrasting finding reveals the importance of ensuring that the preferences of each individual patient with cognitive impairment are considered during the discharge planning process, as there may be a variety of preferences for involvement in the hospital discharge process.

It is evident that clinicians must feel able to challenge unsafe practices that privilege hospital requirements and hierarchies but leave the patient at risk. Alongside this, community resources and hospital discharge policies that enable positive and safe hospital discharge practices must be available (Huby et al., 2004; Kable *et al.*, 2015; Kaiser and Kaiser, 2017). Without these resources health and social care professionals will continue to struggle in their support of people living with dementia during hospital discharge.

Gaps in the evidence base for people living with dementia and their carers include looking at positive experiences of the hospital discharge process and what facilitates this, wellbeing and how it can be supported during the discharge process by nursing staff and interventions which can improve the experience of discharge for people living with dementia. Significant further research is required which includes people living with dementia as participants.

Reflecting on the findings of both the patient and carer synthesis, reveals that this study’s focus on wellbeing addresses a significant gap apparent within the evidence base. The concept of wellbeing has not been investigated within this context, and previous studies have often focused narrowly on the notions of inclusion or exclusion with the decision-making process. The often- negative experiences identified, with the acknowledgement that there may be some negative bias within the data collection process, illuminate the context in which this research study takes place. The synthesis suggests that there is a significant requirement for research which focuses on how to maintain wellbeing, for people living with dementia and their carers, during this process to enable the fulfilment of future changes in policy and practice that will counteract current poor experiences.

The absence of any qualitative evidence regarding the impact of COVID 19 on the hospital discharge process for people living with dementia, also reveals the importance of the data from the study, and its ability to reveal how people living with dementia and their carers, experienced the discharge process during the pandemic. Being able to access this information will enable policy makers and clinicians to understand the impact of the pandemic and adopt policies which would lessen the impact of any future pandemic conditions. It is unfortunate that the study cannot further the evidence base, regarding the experience of people living with dementia, with data obtained from those individuals themselves. This was not possible during the COVID 19 pandemic due to the social distancing legislation and the limits of technology.

2.5.1 Limitations and strengths of the systematic review process

The involvement of two reviewers in the screening process is identified as a strength of the review process as decisions relating to inclusion were discussed in a series of meetings between the reviewers. The agreement between the reviewers meant that there was no need for further review of the studies included. However, the extraction and synthesis was completed by one reviewer (LP). The systematic review process would have been strengthened by the inclusion of a second reviewer. Only studies in English were included in the review. Therefore, relevant studies in other languages may have been missed.

2.5.2 Limitations of and strengths of included studies

Several studies involved only isolated case studies which are indicative of the experience of people living with dementia but are not comprehensive enough to fairly represent patient experience (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). Several of the studies included only a small number of participants, and only 7 of the primary research studies involved people living with cognitive impairment directly. However, a few of the included studies involved in depth and rich data analysis of interviews or ethnographies of people living with dementia, and this represents a strength of the included studies and subsequent findings (Emmett et al., 2014; Dyrstad, Laugaland and Storm, 2015; Digby, Lee and Williams, 2018b).

2.5.3 Factors that should guide health and social care professionals in their support of wellbeing during the hospital discharge process for people living with dementia.

It is clear from the findings of the meta-ethnography synthesis that health and social care professionals are advised to:

- Ensure that discharge planning discussions include people living with dementia, and not only their relatives, to avoid the experience of anxiety and distress for excluded patients.

- Prevent considerations of risk from dominating hospital discharge decision making.

- Work to ensure that discharge goals are formulated with patients and carers and not solely by health and social care professionals in isolation.

- Be empowered to take responsibility for challenging premature or unsafe discharge practices, which prioritise the needs of the hospital above those of the patient.

- Take further responsibility for the day of discharge, including the provision of the correct medication for the patient, to prevent post discharge medication errors.

On an organisational level, it is advisable for the discharge initiatives and policies available to support effective and safe discharge for people living with dementia.

The findings of the systematic review synthesis reveal the experience of people living with dementia and their carers during the hospital discharge process in the pre-pandemic context. It is evident that people living with dementia and their carers are often excluded from the discharge planning process and have negative experiences of the discharge due to a range of different factors. One of the objectives of this research was to conduct a qualitative systematic review to identify and synthesise available evidence, regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. This has been achieved within this chapter. However, as identified above, there was no literature identified that explored the impact of the pandemic, and the gap in the literature regarding research into the nature of wellbeing during the discharge process for people living with dementia and their carers was identified. In the next chapter, I will identify the policy available in relation to the hospital discharge process, and the policy that was issued during the COVID 19 pandemic relating to the hospital discharge process in England.

Chapter 3. Exploration of policy context

3.1 Introductory paragraph

The hospital discharge process is governed by the policy issued to guide clinicians and NHS Trusts in their practice. This research study is based in England and therefore, the guidance available in the English context will be explored. It is important to understand the policy in existence during the research study to identify the impact of such policy on the discharge process and the practice of health and social care professionals. Understanding the policy available also enables a greater understanding of carer, and health and social care professional, experiences. This chapter will first explore the different definitions available of the hospital discharge process. It will then outline the interpretivist approach to policy review and explore the policy documentation available related to the hospital discharge process for people living with dementia and their carers. Following this, the chapter will contrast the content of the policy issued during the COVID 19 pandemic, to previously established policy, to explore the differences in approach during this period. This will help illuminate the context of the empirical data.

3.2 Definitions of the discharge process

A brief look at the different definitions of hospital discharge reveals contradictory perspectives and approaches to the process of leaving the hospital. In the USA, the John Hopkins Medicine organisation defines the discharge process in terms of being instructed as to when you can leave the hospital and the end of the need for inpatient care:

> *'When you leave a hospital after treatment, you go through a process called hospital discharge. A hospital will discharge you when you no longer need to receive inpatient care and can go home. Or a hospital will discharge you to send you to another type of facility.'*
>
> *(John Hopkins Medicine, 2022)*

The NHS definition is much broader with more emphasis on patient and carer involvement in the discharge process.

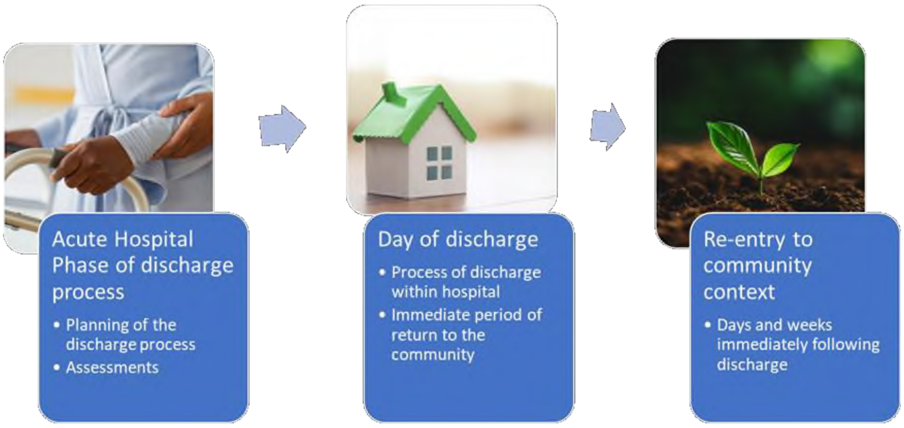
> ‘*Once you're admitted to hospital, your treatment plan, including details for discharge or transfer, will be developed, and discussed with you. A discharge assessment will determine whether you need more care after you leave hospital. You should be fully involved in the assessment process. With your permission, family or carers will also be kept informed and given the opportunity to contribute.’*
>
> *(NHS England, 2022a)*

It is worth noting that the span and scope of the definition of hospital discharge differs in these two different characterisations. The American version identifies the discharge as a discreet period at the end of the hospital stay (John Hopkins Medicine, 2022). The NHS definition is much wider in scope and time. It places the person being discharged and their family at the centre of the process and suggests that the discharge planning process takes place over a longer period (NHS England, 2022a). It is worth noting that within this research project the span of the discharge process is defined even more broadly than either of these definitions. It is contended that the discharge process should be defined as including the immediate period after the person leaves the hospital period. This is a period of readjustment and of re-entering the community, potentially to a different setting due to the changes in condition caused by the period before the hospital stay, or the hospital admission itself.

For a person living with dementia, the chance of readmission to the hospital within 90 days of the discharge is very high. Exact re-admission figures are unclear. A systematic review published pre-pandemic suggested an international re-admission figure anywhere between 7 and 35% for people living with dementia (Ma *et al.*, 2019). A UK report by Dementia Action Alliance suggested a 25% readmission rate in the UK (Dementia Action Alliance, 2013). Whichever of these figures is accurate is somewhat irrelevant, as even the lowest figure suggests that often the discharge process is not successful for people living with dementia and should include this immediate period after physically leaving the hospital, as this represents a litmus period for whether the discharge process has been effective. It is important to note that some readmission will occur for legitimate reasons.

A recent quantitative study of data from a large London hospital suggested that within two years of being diagnosed, 75% of people living with dementia will be admitted to hospital (Sommerlad *et al.*, 2019). Therefore, it is highly likely that most people living with dementia will experience the process of hospital discharge. The discharge process for people living with dementia is significantly more complex than the average hospital discharge for people who do not live with dementia, or have entered the hospital for treatment (Mockford, 2015). People with dementia are more likely to need social care or residential care, may no longer have capacity, and may have significant co-morbidities on leaving the hospital (National Institute for Health and Care Excellence, 2022). Therefore, the hospital discharge process must be appropriate and supportive of this patient group.

The discharge process can be characterised as having three distinct stages as demonstrated in Figure 4 which diagrammatically depicts the discharge process.



Creative Comms Images 2022

Figure 4. Diagram of stages of the discharge process

Understanding and constructing the discharge process in this way allows the full experience of the discharge process, as understood by the person living with dementia and their family, to be analysed. In alliance with the social constructionist ontology of this research project, the discharge process will have different fundamental meanings for different stakeholders involved, but illustrating the discharge process in the manner provided allows for the most comprehensive overview in relation to this project.

Before discussing the policy specific to the discharge process for people living with dementia and their carers it is important to explore the concept of the ‘delayed discharge’ and the role this plays in how people living with dementia are often conceptualised in the hospital sphere.

3.3 Delayed discharge

There is an acceptance in practice and policy literature that people living with dementia often function as ‘bed blockers’ within acute general hospitals. This is a value laden term (Leighton, 2002), which suggests that people living with dementia are in hospital when they should not be and are preventing other members of the population accessing services (Manzano-Santaella, 2003). The term ‘bed-blocker’ is largely unused in recent policy and practice literature due to the pejorative nature of the term. The Department of Health began using the phrase ‘delayed transfer’ in 2002 as an answer to the stigma surrounding the term.

The ‘delayed transfer’ has been identified in the literature as problematic. Both Digby, Lee and Williams (2018) and Manzano-Santaella (2003) identify that this is because the UK Government selected reduction in length of stay as an efficiency tool. Bed occupancy targets entail that hospital culture desires a rapid movement of patients through the system to reduce costs. People living with dementia move more slowly through the system and, as such, are considered a hinderance to efficiency and given a diminished and pejorative status within the hospital. Kumar, Shinge and Parameshwar (2010) identified that the average length of stay considered to be ‘bed-blocking’ was 31 days, but this is a subjective description.

The NHS has clear definitions regarding the nature of a ‘delayed discharge’. The Hospital Discharge and Community Support Guidance from the Department of Health and Social Care (2022e) has very narrow criteria for remaining in hospital. The criteria are medically orientated and have very limited scope. They include: ‘being 24 hours away from invasive surgery or requiring ITU or HDU care? requiring oxygen therapy? requiring intravenous fluids? NEWS2 greater than 3? (clinical judgement required in persons with Atrial Fibrillation and/or chronic respiratory disease) diminished level of consciousness where recovery is realistic? acute functional impairment in excess of home/community care provision? last hours of life? requiring intravenous medication > b.d. (including analgesia)? Having undergone lower limb surgery within 48 hours? Having undergone thorax-abdominal or pelvic surgery with 72 hours? within 24 hours of an invasive procedure? (with attendant risk of acute life- threatening deterioration)’ (Department of Health and Social Care, 2022e, p. 41). Such a limited criterion for remaining in hospital entails that many patients can be routinely identified as ‘bed- blockers.’

Manzano-Santaella (2003) identifies that within practice literature there are two main reasons normatively given for the bed blocking phenomenon. A failure in the discharge planning process, this approach generally blames social services for failing to offer timely resource, or a shortage of care within the community. This interpretation is evident in a significant amount of the literature in this area. Gaughan, Gravelle and Siciliani (2015) identify that there is a significant relationship between limited care home placements and the number of delayed discharges. Similarly, Holmås, Islam, and Kjerstad (2013) identify that there is a relationship between the expansion of social service provision and a reduction in delayed discharge. However, other evidence disputes these findings.

Carter *et al* (2004), argues that there are many factors involved in why an individual’s discharge may be delayed across both the hospital and community setting. Glasby, Littlechild and Pryce (2004) acknowledged that delays are often caused by waiting for interprofessional meetings or specialist input. These findings are at odds with the reasons usually conceptualised as to why a patient may ‘bed block’. Carter and Wade (2004) argued that the concept of a ‘delayed discharge’ itself is flawed, as it is subjectively decided by individual physicians. Vetter (2003) argues that there is no way to define a delayed discharge, as there is no way to distinguish what is an inappropriate delay. Further to this, Clark and Rosen (2001) argue that the concept of the delayed discharge is a mistaken one. Instead, they argue that the idea that hospital stays should be short and efficient is flawed, and instead that some patients should have longer stays as they can be beneficial. However, as the concept of delayed discharge is embedded in policy literature, it is difficult for people living with dementia to avoid the stigma of the concept of delayed discharge.

3.4 Interpretivist approach to policy review

A review of the health and social care policy documentation is crucial to understanding the context in which the hospital discharge process is situated. I returned to policy documentation at different stages of the PhD project. These stages included: during the initial development stages of the research project; following the data collection phase; and during the analysis process. Exploring theorists such as Bowen (2009), Bletsas (2012), Silverman (2015) and Fischer *et al.* (2015), helped with the identification of the type of policy analysis relevant to understanding the data collected.

It was identified that an interpretative approach would enable the exploration and explanation of the key policies underpinning the discharge process, in a manner complimentary to the ontology of the research project (Browne *et al.*, 2018). This approach contrasts with other policy analysis approaches which can have a positivist focus, and examine areas such as cost-benefit analysis, implementation approaches or how and why a policy is developed and whether it is objectively ‘successful’ (Browne *et al.*, 2018). The method of document review outlined by Bowen (2009), which adopts an iterative process combining elements of both thematic and content analysis has been implemented in this chapter. A practical, firmly qualitative approach to policy document review, outlined in detail by Cardno (2019) has also been employed. This approach recommends reviewing a document through three key areas: policy context, policy text and policy consequences.

The definition of policy context includes exploring the political climate and socio-economic environment leading to the formation of the policy (Cardno, 2019). Analysis of the policy text comprises of: investigating what is stated within the policy; inferences about theories and values that may be influencing the actual text; language use within the document; the overall structure of the document; and identifying what is not stated transparently within the text but may be implied or even omitted within the document (Silverman, 2015). Policy consequences include how the individuals implementing the policy understand it, unexpected outcomes, and the potential challenges of implementation which the researcher can identify (Bletsas, 2012). This is a critical and evaluative approach to policy analysis which allows the policy to be interrogated for its underpinning influences and purposes. Some of these areas may not be explicitly stated or even obvious on first reading of the documentation. This approach has allowed for the consideration of the three domains explicitly during the analysis of the policy documentation and enabled the contrast of the documentation produced before and during the pandemic. This revealed the 'gaps' evident within the documentation, and the explicit and implicit focus of pandemic policy, in comparison to earlier policy publications in this subject area. The next section of this chapter will outline how using this interpretivist approach helped with understanding the policy produced, before and during the pandemic, in a manner that contextualised the data collected.

3.5 The discharge process

3.5.1 Context

This section will begin by outlining the context in which hospital discharge policy has developed, before moving on to consider the text of the policy that has been issued in the last 10 years, and finally the consequence of the policy guidance. The past 20 years have seen radical metamorphosis of health and social care in England. Successive governments have moved away from the founding principles of the NHS towards a neo-liberal approach which places emphasis on competition, marketisation and individual responsibility (Delamothe, 2008; Department of Health, 2012; Allen *et al.*, 2017). These changes have been met with criticism and the argument that the new emphasis on choice is really a smoke screen for a move towards greater responsibility for the individual (Department of Health, 2012; Den, Exter and Guy, 2014). The discharge process has not been immune to these changes and has altered to reflect the realities of leaving the hospital in the twenty-first century. The process has transformed to meet the reality of a growing population of older adults, leaving the hospital with a dementia diagnosis, and the many health and social considerations which must be addressed during this process.

Several different guidance documents (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; National Institute for Health and Care Excellence, 2018) have been issued in response to this changing context to ensure that the discharge process is appropriate for this patient/carer group in the twenty- first century. These publications are listed in figure 5 alongside policy issued during the COVID 19 pandemic. Publications (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; National Institute for Health and Care Excellence, 2018) outline expectations about how the discharge process should operate for adults with social care needs. This includes people living with dementia. It is noted that this guidance is not specifically for the population living with dementia. It could be argued that the generality of the National Institute for Health and Care Excellence (NICE) guidance, in relation to the discharge process, could benefit from more specificity in relation to dementia conditions. This is due to the unique implications of the condition, and the reality that nearly 33% of individuals being admitted to hospital will have a dementia diagnosis in 2022 and 2023 (Office for Health Improvement and Disparities, 2022).

People living with dementia are at high risk of adverse events during both the hospital admission period and during the discharge process, due to the impact of the condition on cognition (Fog, Griffiths, Meredith, and Bridges, 2018). Kable *et al* (2019) identified the vulnerability of people living with dementia to medication errors during this period. Further to this, Neziraj *et al* (2021) identified that individuals in dementia care units had a higher vulnerability to pressure ulcers, malnutrition, poor oral health, and falls. This longitudinal study highlights the unique implications of this condition for this patient group and their specific vulnerabilities due to the cognition impact of dementia.

People living with dementia have more complex needs than patients who do not live with dementia due to the impact of the condition on their short- and long-term memory, the impact of the progressive condition on mobility, and ability to attain adequate nutrition; the potential to experience hallucinations and problems with language and communication (Alzheimer's Society, 2023). The impacts described above are not generally present in patients without cognitive impairment, even if they require social care input or would be described as frail. Therefore, specific guidance that considers the impact of these complex presentations would be beneficial to aid people living with dementia in a more targeted and person-centred way.

Why the decision to issue hospital discharge guidance for such a broad population, unaccompanied by a smaller subsection of more nuanced guidance directed at people living with dementia, was taken is unclear. Recent research has explored the potential impact of a patient and public involvement group on the development of policy relating to hospital guidance (Malfait *et al.*, 2018). The involvement of individuals with lived experience would offer a potential route to developing a more specialised subsection of guidance. The need for specific guidance for individuals living with dementia and their carers will be justified by the increasing number of people living with the condition, and its status as the number one cause of death within the UK (Office of National Statistics, 2022). This number will significantly increase over the next ten years based on current predictions (Alzheimer's Research UK, 2018). It should be noted that the 2018 guidance- 'Dementia: assessment, management and support for people living with dementia and their carers' (National Institute for Health and Care Excellence, 2018) which is specific to people living with dementia, simply refers to the 2015 and 2016- 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs' National Institute for Health and Care Excellence guidance, without adding anything new in relation to the discharge process specifically.

Five quality statements were issued by the National Institute for Health and Care Excellence (2016) that should be adhered to during the discharge process of adults living with dementia with complex needs from the acute hospital setting. They are outlined in Extract 1. This extract has been selected as it outlines the central tenets of the actions that should be taken during the discharge process. The discharge process, as defined by the guidance issued in 2015, chooses to characterize the discharge process beyond the physical leaving of the hospital space, and into the initial period settling back into the community. This is in accordance with the definition of this research project (National Institute for Health and Care Excellence, 2015). The key policy statements of the guidance aimed at older adults, living with dementia with complex needs, being discharged from an acute hospital (National Institute for Health and Care Excellence, 2016) are outlined in Extract 2. Extract 2 has been included as it outlines some of the central responsibilities of the hospital discharge team to ensure that bed pressures are not the primary driver of discharge, and that carers and family are involved in the discharge process and safeguarded. These tenets are important because there is independent evidence revealing the negative impact of discharging due to bed pressures, or decision making in crisis (Friebel *et al*, 2019). The importance of relative and carer involvement in discharge planning is established within wider literature and government guidance (Hesselink, 2014, NHS England, 2023).

Extract 1 Transition between inpatient hospital settings and community or care home settings for adults with social care needs**.** Quality statements. (National Institute for Health and Care Excellence, 2016)

Statement 1: Adults with social care needs who are admitted to hospital have existing care plans shared with the admitting team.

Statement 2: Older people with complex needs have a comprehensive geriatric assessment started on admission to hospital.

Statement 3: Adults with social care needs who are in hospital have a named discharge coordinator.

Statement 4: Adults with social care needs are given a copy of their agreed discharge plan before leaving hospital.

Statement 5: Adults with social care needs have family or carers involved in discharge planning if they are providing support after discharge.

(National Institute for Health and Care Excellence, 2016)

Extract 2 Transition between inpatient hospital settings and community or care home settings for adults with social care needs (National Institute for Health and Care Excellence, 2015)

1.5.11 Ensure that people do not have to make decisions about long-term residential or nursing care while they are in crisis.

1.5.12 Ensure that any pressure to make beds available does not result in unplanned and uncoordinated hospital discharges.

1.5.15 The discharge coordinator should ensure that the discharge plan takes account of the person's social and emotional wellbeing, as well as the practicalities of daily living.

1.5.29 The hospital- and community-based multidisciplinary teams should recognise the value of carers and families as an important source of knowledge about the person's life and needs.

1.5.31 If the discharge plan involves support from family or carers, the hospital-based multidisciplinary team should take account of their: willingness and ability to provide support; circumstances, needs and aspirations; relationship with the person; need for respite.

1.5.32 A member of the hospital-based multidisciplinary team should discuss the practical and emotional aspects of providing care with potential carers.

(National Institute for Health and Care Excellence, 2015)

The text of the 2016 quality standards (National Institute for Health and Care Excellence, 2016) reveals what is valued, for adults living with dementia, during the acute hospital discharge process. The emphasis on assessment, a discharge co-ordinator and an agreed discharge plan reveals that extensive planning is highly valued. The involvement of the family or carers of adults with social needs within the fifth statement, indicates that there is an acknowledgement of the importance of genuine and meaningful involvement from carers and family within the discharge planning process. The detail of a comprehensive geriatric assessment also reveals that the standard is looking to move the discharge process beyond a focus on simply medical concerns.

No external review of the implementation of these quality standards has been undertaken. It is difficult to assess how these standards have been adopted and whether they are adhered to in practice. Quality standards such as these are aimed at improving care standards, but as stated within the text of the document, ‘expected levels of achievement for quality measures are not specified’ (National Institute for Health and Care Excellence, 2016, p. 22). Therefore, it is challenging to assess whether they have been successfully implemented.

The 2015 guidance is appreciative of the role and expertise of the carer within the discharge process and the requirement for their needs, including the requirement for adequate respite, to be considered, and for appropriate support and training to be offered. This is detailed in section 1.5.29 and 1.5.32 (National Institute for Health and Care Excellence, 2015). Furthermore, the importance of not choosing long term residential accommodation when in crisis is emphasised in section 1.5.11 (National Institute for Health and Care Excellence, 2015). There is an emphasis on the requirement for a discharge co-ordinator, who can provide a point of contact and be the link between the community and the hospital, and this is emphasised in section 1.5.1 (National Institute for Health and Care Excellence, 2015). There is also the clear statement not to put the pressure for hospital beds above the need for a well-planned and co-ordinated discharge in section 1.5.12 (National Institute for Health and Care Excellence, 2015). It is important to note that these aspects of the guidance highlight the policy’s aim to support the needs of the patient and the carer during the discharge process. It is important to identify the content of the National Institute for Health and Care Excellence guidance (2015) in contrast to the policy guidance issued during the pandemic.

One of the most telling aspects of the guidance is the emphasis placed on ensuring wellbeing during the discharge process in section 1.5.15 (National Institute for Health and Care Excellence, 2015). This places an emphasis on the discharge co-ordinator to consider the wellbeing of the person living with dementia. The recommendations also ask for, ’a better experience of transitions between hospital and home’ (National Institute for Health and Care Excellence, 2015, p. 21), and place a clear emphasis on carer wellbeing alongside patient wellbeing. It is argued in the implementation section, in relation to person centred care that, ‘carers specialist understanding of the person living with dementia is realised and that carers are helped to protect their own wellbeing’

(National Institute for Health and Care Excellence, 2015, p. 19). Further to this, there is a requirement to promote wellbeing placed on health and social care professionals, (National Institute for Health and Care Excellence, 2015).

The guidance is very transparent about the requirement for wellbeing, beyond physical needs, to be addressed within the discharge process. It is unfortunate that how to support wellbeing during the discharge process is not outlined. This causes the term wellbeing to remain opaque for both carers and people living with dementia. In the previous section, the potential of patient and public involvement to delineate specific guidance in relation wellbeing was identified (Malfait *et al.*, 2018). This offers a potential route to more detailed guidance regarding how to support wellbeing during the discharge process and could be added as an addendum to the more general guideline.

If the omission of detail and clarity, in relation to how to support wellbeing in practical terms is deliberate, then the motives for this must be considered. Wellbeing is defined within the Care Act (2014) (see definition in Extract 3) but in very broad terms only, with an emphasis on individual responsibility centralised. It is not defined as a term specifically for individuals living with dementia, or their carers, nor is it defined in specific contexts. In the next section of this chapter, I will outline some of the consequences of the impact of policy documentation available before the pandemic, and progress to discussing the policy issued during the COVID 19 pandemic.

Extract 3 Wellbeing definition from The Care Act (2014)

Wellbeing as defined in The Care Act (2014)

Well-being”, in relation to an individual, means that individual’s well-being so far as relating to any of the following—

(a) personal dignity (including treatment of the individual with respect);

(b) physical and mental health and emotional well-being.

(c) protection from abuse and neglect.

(d) control by the individual over day-to-day life (including over care and support, or support, provided to the individual and the way in which it is provided).

(e) participation in work, education, training or recreation.

(f) social and economic well-being.

(g) domestic, family and personal relationships.

(h) suitability of living accommodation.

(i) the individual’s contribution to society.

(Department of Health, 2014a)

3.5.2 Consequence

The requirements of the 2015 guidance reflect the necessity for adequate organisation within the discharge procedure, and a process which values the involvement of carers. However, a significant criticism of the guidance is that wording and meaning is vague. An example of this is, ‘health and social care organisations should agree clear discharge planning protocols’ (National Institute for Health and Care Excellence, 2015, p. 11). There is no clarity concerning what those protocols should include. There is also very vague advice related to communicating with and supporting carers in section 1.5.7. (National Institute for Health and Care Excellence, 2015, p. 11). The advice provided suggests that support and training could include a face-to-face meeting with practical training, or only the provision of a leaflet.

These forms of support are very different in character. A consequence of the flexibility to provide a face-to-face meeting, or a leaflet, will ensure significant diversity in provision across the UK, with different hospital trusts free to make different decisions. It could be argued that the support carers will experience will be significantly different if offered a face-to-face meeting, versus a leaflet. The lack of detail included in the 2015 guidance (National Institute for Health and Care Excellence, 2015) could be linked to a desire not to commit to any specific actions, but instead allow individual health and social care settings to interpret guidance however they choose. The consequence of this could be that the lack of guidance available may lead to confusion in practice, and possibly an omittance of wellbeing considerations during the discharge process, due to the absence of concrete and detailed recommendations for specific actions.

If we turn our attention to the 2016 quality standards (National Institute for Health and Care Excellence, 2016), it is important to note that each standard is defined in a multitude of ways within the guidance. Each standard indicates separately what the standard will mean to commissioners, health and social care practitioners and people living with dementia, or with other conditions which can render patients, and their carers vulnerable. A consequence of this approach is that it indicates a social constructionist understanding of what the discharge process is and how it operates.

This acknowledgement that the quality standards have different meanings for different individuals involved in the discharge process, reveals the subjectivity of discharge, and the importance of taking an approach to assessment that allows for diverse opinions and perspectives. It indicates that the only meaningful review would be one that was qualitative, and approached the topic of discharge from an ontology that acknowledged the multitude of perspectives involved in leaving the hospital. In accordance with this, during this research project the quality standards will be considered and whether the quality standards are being upheld in the opinion of the researcher will be addressed in the discussion section of this thesis.

The 2015 and 2016 NICE guidance remains ambiguous partly because of the wide population it is aimed at. The guidance is primarily for adults requiring social care, not specifically people living with dementia. There is some information included referring to homelessness and the requirements of individuals who have experienced a stroke. Generally, people living with dementia experience a capacity assessment close to discharge (Emmett *et al.*, 2013), and this has been flagged in previous research as an area that requires further attention during the discharge process. However, there is no in-depth consideration of this issue which leaves the task of assessing capacity particularly vague during the discharge process. As previously argued, the guidance would benefit from a specialised subsection that addresses the needs of individuals living with dementia and their carers. It has been identified that people living with dementia and their carers have very specific requirements that should be considered (Emmett *et al.*, 2013), and this is not currently possible because of the guidance available. The input of public advisors in the compiling and drafting of subsequent guidance, may offer a potential approach to tackle this lack of specificity.

During the formulation of this research project, the guidance available was reviewed as the primary policy documentation regarding how the discharge process should function to support carer and patient wellbeing (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2018). The limitations of the guidance were noted but the usefulness of the guidance, as a place to consider and compare the practice observed, and the experiences of carers and professionals was appreciated. However, during the first year of the project new guidance was issued which was to have a significant impact on the discharge process. The next section of this chapter will explore and review the discharge policy formulated by the UK Government at the beginning of the pandemic and compare it to previous guidelines.

3.6 COVID 19 policy and the discharge process

The infographic in Figure 5 details the policy documentation released since 2015 relevant to the discharge process and people living with dementia.

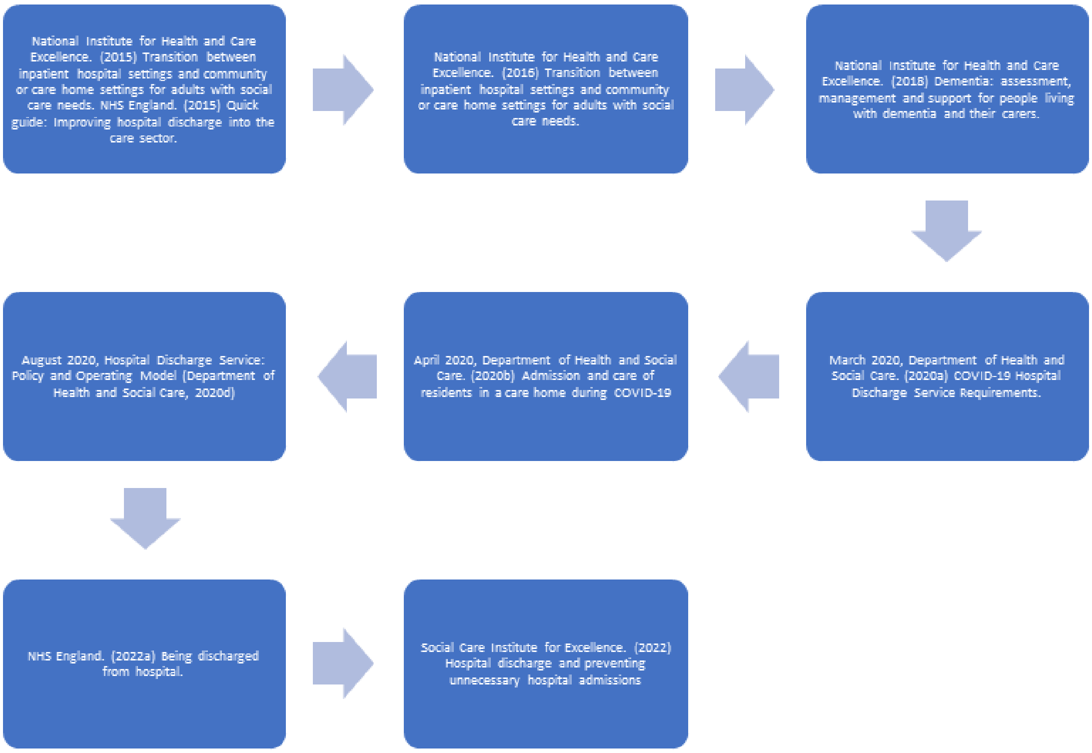


Figure 5: Infographic of UK policy documentation related to the discharge process since 2015.

3.6.1 Context

In March 2020, new policy and guidance was issued in response to the COVID 19 pandemic which was to have a significant effect on the discharge process and people living with dementia and their carers. In response to the threat of COVID 19, in March 2020 the UK Government issued guidance which aimed to discharge all patients who were medically fit as soon as possible (Department of Health and Social Care, 2020a). Some of the key aspects of the first pandemic policy guidance related to the discharge process and issued in March 2020 are presented in Extract 4. Extract 4 has been included as it succinctly outlines the expectations of the UK government regarding the rapid discharge of patients during the onset of the COVID 19 pandemic.

3.6.2 Text

Extract 4 March 2020 Section 1.3 COVID-19 Hospital Discharge Service Requirements (Department of Health and Social Care, 2020a).

- Acute and community hospitals must discharge all patients as soon as they are clinically safe to do so. Transfer from the ward should happen within one hour of that decision being made to a designated discharge area. Discharge from hospital should happen as soon after that as possible, normally within 2 hours.

- For 95% of patients leaving hospital this will mean that (where it is needed), the assessment and organising of ongoing care will take place when they are in their own home.

- For patients whose needs are too great to return to their own home (about 5% of patients admitted to hospital) a suitable rehabilitation bed or care home will be arranged. During the COVID-19 pandemic, patients will not be able to wait in hospital until their first choice of care home has a vacancy. This will mean a short spell in an alternative care home and the care coordinators will follow up to ensure patients are able to move as soon as possible to their long-term care home.

- During the COVID-19 pandemic, all of the above support will be paid for by the NHS, to ensure patients move on from their acute hospital stay as quickly as possible'.

3 Central Questions

- Why not home?
- What needs to be different to make this possible at home?
- Why not today?

(Department of Health and Social Care, 2020a)

Section 1.3 of the guidance issued in March 2020 (Department of Health and Social Care, 2020a), argued for rapid discharge once it was clinically safe to do so, and the development of specific discharge areas (Department of Health and Social Care, 2020a). This guidance, designed to 'free up' beds, revamped the discharge process from one where assessments took place on the ward to a model where patients were moved to the discharge lounge, and assessed in a community bed, or within the home, after leaving hospital. Funding was made available to facilitate this new, faster discharge process and this was outlined in section 2.6 of the new guidance. It was also stated that individuals should not wait in hospital but be discharged to interim beds if necessary to facilitate their removal from the hospital. There is very little mention of testing for COVID 19 before discharge, in the guidance issued in March 2020, except to state that test results should accompany patients on discharge 'where applicable' (Department of Health and Social Care, 2020a, p. 8). The 'discharge to assess' model introduced within the guidance to speed up the discharge process, asked clinicians to refer to three key questions every day outlined in Extract 4.

3.6.3 Consequence

It is evident that the March 2020 guidance places the requirement to empty beds within the hospital as the central concern, above the welfare of patients, particularly those with needs requiring residential care post discharge. Rehabilitation beds or alternative care home placements were prioritised to ensure a quicker discharge. Moving people living with dementia multiple times has long been identified as problematic (Moyle *et al*., 2008) and consequently, this guidance was clearly detrimental to people living with a dementia.

The focus of the policy on ensuring that patients left the hospital space and explicit mention of ‘positive risk taking’ (Department of Health and Social Care, 2020a, p. 28) ensured that the discharge atmosphere was not focused on person centred care during this period but rather the requirement to discharge speedily.

The limited guidance regarding COVID 19 testing at discharge within the March 2020 guidance (Department of Health and Social Care, 2020a), led to hospital discharges taking place without any COVID 19 testing. A consequence of the ‘discharge lounge model,’ was that patients who were being discharged moved from one ward setting to a communal discharge lounge setting, without any testing for COVID 19 occurring. There was no consideration of testing before entry to a care home, and no discussion around isolation in the guidance issued in March 2020. The extra movement of people living with dementia into a discharge lounge, and the impact this would have on their wellbeing was also not considered.

3.7 Further policy related to the hospital discharge process issued during 2020 in response to the pandemic.

Extract 5 August 2020 Hospital Discharge Service (Department of Health and Social Care, 2020d)

‘Ensure COVID-19 testing of all people being discharged from hospital to a care home, in advance of a timely discharge (as set out in the Coronavirus: adult social care action plan). Where a test result is still awaited, the person will be discharged if the care home states that it is able to safely isolate the patient as outlined in Admission and Care of Residents in a Care Home guidance’.

‘On decision of discharge, the person and their family or carer, and any formal supported housing workers should be informed.’

(Department of Health and Social Care, 2020d)

The UK government continued issuing guidance, in relation to the hospital discharge process, throughout the pandemic including in August 2020 (Department of Health and Social Care, 2020d) (Extract 5). Guidance was issued 04 April 2020 (Department of

Health and Social Care, 2020b) which began to identify the requirement for testing prior to a discharge from the hospital setting, into the care home setting. This document had been withdrawn by the time of drafting this thesis, and the document accessible to the public had been updated many times since first issued to reflect the changes in isolation periods over the latter period of the pandemic. The final update was added in March 2022. During the editing process of this thesis, it became apparent that it has since been withdrawn as of 1 April 2022. This document (Department of Health and Social Care, 2020b) referenced the wellbeing definition from The Care Act (Department of Health, 2014a) as being an important consideration during the discharge process, but it is difficult to identify when this was added as a clause, due to the numerous updates to the guidance. The documentation issued on April 15, 2020 (Department of Health and Social Care, 2020b), mentioned at section 1.3, that testing will shortly be instated before discharging people living with dementia from the hospital to a care home, but explicit plans are not detailed at that point. There is also no explicit discussion of wellbeing in this document at this point.

The guidance issued in August 2020 (Department of Health and Social Care, 2020d), is in marked contrast to the March 2020 documentation (Department of Health and Social Care, 2020a). Testing for COVID 19 and isolation requirements, if being discharged to a care home, are explicitly outlined, and included in Extract 5 (Department of Health and Social Care, 2020d, p. 18). This has been included as an extract to explicitly highlight when testing and isolation was established within policy guidance, and the beginning of the change of direction from rapid discharge to more measured actions with a wellbeing focus. Section 2.10 details the ongoing financial support available to promote quicker hospital discharge during the pandemic period. In the next section, the policy issued during the pandemic will be compared with the guidance issued in the post pandemic period.

3.8 Comparison of March and August 2020 guidance with 2015 and 2016 policy documentation

The tone and format of the guidance issued in March 2020 (Department of Health and Social Care, 2020a) and August 2020

(Department of Health and Social Care, 2020d) differs markedly from guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016). The emphasis of the 2016 and 2015 guidance on wellbeing, for both patients and carers, is missing in the guidance issued during the pandemic in its early stages. The stated goal of the 2015 guidance in section 1.5.12 (National Institute for Health and Care Excellence, 2015) to ensure that the need for available hospital beds is not put above the wellbeing of the patient, and that there is a well-planned, well-co-ordinated hospital discharge, is entirely contradicted by the guidance issued in March 2020 and August 2020 (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020d). Pandemic policy prioritised the requirement to discharge quickly and liberate hospital beds above all other needs including wellbeing. The subjective positioning of the guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016) which acknowledged multiple perspectives, including those of carers, patients, and other stakeholders, is not evident in the guidance issued in March 2020 and August 2020 (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020d). The tone and approach of the guidance follows the medical paradigm, which views the discharge process as a specifically medical process aimed at removing a ‘well’ patient from the acute environment to a community setting.

There is mention in the guidance issued in August 2020 (Department of Health and Social Care, 2020d) that relatives and carers should be merely informed when their relative is going to leave hospital. This could not be more different from guidance issued in 2015 and 2016 (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016), which emphasised the importance of joint and shared decision making between carers, people living with dementia and health and social care professionals. Statement 5 of the 2016 guidance (National Institute for Health and Care Excellence, 2016) provided clarity regarding the importance of this joint working and decision making, at all times, during the discharge planning process. This small example highlights the significant differences in policy issued pre-pandemic, and the policy drafted during the pandemic. The priorities of pandemic context guidance are evident and do not include wellbeing as defined in The Care Act (2014). The consequences of these priorities were evident in the early months of the pandemic. In the final section of this chapter, we will consider the policy that has been released in the aftermath of the pandemic, and how wellbeing has been positioned more recently in policy related to the discharge process.

3.9 Review of guidance released in the aftermath of the pandemic impact.

Extract 6

The Social Care Institute for Excellence Hospital discharge and preventing unnecessary hospital admissions (COVID-19) (Social Care Institute for Excellence, 2022)

‘Rapid hospital discharge and avoidance, especially in the early months of the pandemic resulted in deaths, trauma, limits to people’s freedom and choices, and many people not getting support that is right for them’.

‘What can be done quickly and safely to improve people’s health and wellbeing?’

(Social Care Institute for Excellence, 2022)

The Social Care Institute for Excellence (2022) produced a report aimed at commissioners, and updated in January 2022, which acknowledged that the emphasis on quick discharge at the beginning of the pandemic led to deaths, limits on freedom and choice, and many not receiving the correct support (Social Care Institute for Excellence, 2022). Extract 6 has been included because it emphasises how the new guidance for health care commissioners issued in 2022, shares more common ground with previous guidance, than pandemic policy (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016). Wellbeing is once again highlighted as requiring specific consideration (Social Care Institute for Excellence, 2022). The acknowledgment of the mistakes of the earlier guidance outlined in Extract 1 is evident. However, the discharge to assess model is still strongly favoured, and the ‘core principles’ of a good discharge process continue to adhere to the neo-liberal agenda, with leadership, choice, agile and confident leadership, co-production, communication and integration and collaboration (Social Care Institute for Excellence, 2022) being promoted. There is also an emphasis on the voluntary sector which fits the neo-liberal model (Social Care Institute for Excellence, 2022).

The ‘where best next?’ campaign which favours a discharge to assess model to speed up the discharge process is still centralised in current guidance for commissioners (Newton Europe, 2019). However, it was produced before the pandemic period, and its content appears at odds with the most recent report which acknowledges that rapid hospital discharge is problematic. It is also at odds with the recent government decisions to discontinue discharge to assess funding from March 2022 (Social Care Institute for Excellence, 2022). The NHS quick guides to hospital discharge, which are signposted on the guide for commissioners updated in January 2022, are pre-pandemic documents dating from 2015 (NHS England, 2015). These guides identify potential local solutions from individual health economies which seems to support the fragmentation of services into small individual local provisions (NHS England, 2015). It appears that the guidance available concerning the discharge process, and particularly the hospital discharge process for people living with dementia and their carers, requires further attention from policy makers, and substantial re-consideration in the aftermath of the pandemic. New guidance that incorporates an awareness of the drawbacks of a rapid discharge process for people living with dementia and acknowledges that with the discontinuance of funding in March 2022, the discharge to assess model requires re-consideration. It is my contention that the guidance currently available is not fit for purpose.

At this point it must be acknowledged that during the drafting of this thesis and weeks after the above paragraphs were written, on the 27th of April 2022, the High court in England found that the Government’s guidance issued between 17th March 2020 and 4th April 2020 under the then Secretary of State for Health and Social Care was unlawful (Holt, 2022). The guidance was described as a failure of policy (Holt, 2022) that omitted to protect vulnerable older people being admitted to care homes from hospital.

The specific policy documentation discussed within this thesis (Department of Health and Social Care, 2020a), was identified as failing in its duty of care towards older, vulnerable adults in relation to asymptomatic transmission, and the testing of patients being discharged from hospital. The public inquest into this failure is scheduled for some time in 2023 which lies outside of the timeframe of this PhD. It is in the shadow of this policy, which has been identified as unlawful and a failure, that my PhD project was implemented. Many of the professional participants involved in this study were making clinical decisions in the light of the 2020 policy guidance detailed (Department of Health and Social Care, 2020a; Department of Health and Social Care, 2020b), and carer participants were often discussing their experiences in the period in which this guidance was in place. Therefore, it is important to situate the findings presented within this policy context. These contextual policy elements are important to remember when reading the findings of this research project regarding the impact of COVID 19 on the discharge process, and how this impacted on the wellbeing of carers and people living with dementia.

This chapter has provided an analysis of the policy documentation, for people living with dementia and their carers, in relation to the hospital discharge process and wellbeing in both the pre-pandemic and pandemic era. This provides the context of the study and reveals how the guidance was flawed in its ability to promote wellbeing during the discharge process before the pandemic, and how policy issued at the beginning of the pandemic undermined potential efforts to ensure wellbeing within the pandemic era. This chapter has also argued that the policy and guidance published in 2022 is not fit for purpose and needs significant attention to engender a discharge process which can enable the wellbeing of people living with dementia and their carers. The next chapter will progress from the literature and policy context to outline decisions made in relation to the ontology and methodology of this research project. It will trace the original methods identified in 2019, and how these methods changed in response to the pandemic, and the restrictions experienced by all researchers engaged in active data collection during this period.

Chapter 4. Methodology

4.1 Introduction

In this chapter the ontological and epistemological frameworks underpinning the research process and how the research questions are answered will be discussed. The implications of the theoretical approach on the methodology, data collection method and analysis, will be outlined in depth to demonstrate and justify decisions made. The complex ethical process and recruitment procedures had a significant impact on the form and format of the research and will be discussed at length. Furthermore, the details of how the analysis was conducted will be delineated. The positionality of the researcher will be discussed and how a variety of reflexive techniques were utilised to prevent professional biases dominating the analysis process and findings. The impact of the COVID 19 pandemic and how it shaped the research project will also be discussed.

4.2 Theoretical perspectives

4.2.1 First steps in identifying an epistemology/ontology.

This section will commence by outlining how the ontological and epistemological paradigm was selected, why this perspective was chosen, other potential approaches considered and why they were rejected. Identifying this multiplicity of perspectives in relation to the care experience was to have an important influence on my later research interests and focus.

Being involved in a research project into the experiences of people living with dementia in hospital allowed me to identify that there were gaps present within the evidence base, in relation to the hospital care experienced by people living with dementia and their carer/s. There was a dearth of qualitative research exploring different hospital processes for these patients, even though there was an abundance of evidence suggesting negative hospital outcomes in relation to care home admissions and delayed discharges (Healthwatch, 2015; Alzheimer's Society, 2016; National Audit Office, 2016; Fogg *et al.*, 2018). I knew that people living with dementia deserved a better evidence base informing their care, and that their experiences and perspectives be acknowledged and understood within the research community, clinicians, and hospital administrations. There was also a requirement for further policy informed by evidence regarding patient and carer experience.

When drafting my research proposal and applying for funding, I implemented a literature scoping exercise. There was limited published qualitative research focusing specifically on the experiences of people living with dementia and their carers during the hospital discharge process. There was also limited research focused on health and social care professional experiences and opinions of the process. There was quantitative research available showing negative associations between hospital stays, poor discharge experiences and adverse outcomes (Fogg *et al.*, 2018; Age UK, 2016; National Audit Office, 2016; Alzheimer's Research UK, 2018). However, the voice of the patient and their carer was largely absent, as most of the studies focused on quantitative data and results.

4.2.2 Choosing a qualitative approach.

This belief in the need for a multitude of voices and perspectives ruled out the possibility of a quantitative project. I had already identified that quantitative research revealed the link between hospital discharge and negative outcomes. However, the absence of the patient or carer or professional experience in the quantitative data meant that the reason for those negative outcomes was not clear (National Audit Office, 2016; Fogg *et al.*, 2018; Alzheimer's Research UK, 2018). Quantitative research methods are based on an ontology that purports there is only one solution, answer, or experience, that can be identified via a rigorous analytic method devoid of subjectivity (Bruce, Pope and Stanistreet, 2017). My previous experience within the NHS as a staff nurse had revealed to me that there is rarely one answer to patients experiencing poor or positive consequences, and that the relationship between patient outcomes, experience, and professional practice, is an extremely complicated one. Further to this, the data available via quantitative approaches, such as analysing questionnaire data, would not allow for the opportunity to explore the individual experiences and perspectives of carers, patients, and professionals in different fields

(Peat, 2002). The decision to focus on wellbeing, a highly subjective term, would not lend itself well to quantitative methods and approaches either. The necessity of a qualitative approach that appreciated the complexity of the discharge process, and the multitude of perspectives from the individuals involved was evident once I decided on the research aim and objectives.

4.2.3 Identifying an appropriate paradigm.

I spent a significant amount of time exploring the different ontologies, epistemologies and paradigms that underlie modern academic research. This was in some ways a bewildering process for a health care professional entering the philosophical sphere of research. Research methods previously taken at face value, such as questionnaires, interviews, and even clinical trials, suddenly took on a plethora of ontological and epistemological dimensions, aspects and questions. Already knowing that I was interested in exploring different perspectives and experiences and that qualitative methods would suit this approach, I began working backwards to try and understand the ontology and epistemology behind what had felt instinctive to me as a novice researcher.

I began to explore the concept of ontology 'what is the world' and epistemology 'how can we know and understand the world' (Mays and Pope, 2000, p. 17). This is a hotly debated area with differing stances and opinions apparent in different research spheres and fields. The meaning of interpretivism, realism and the epistemologies associated with each differ according to approach and theorist (Flick, 2006; Bourgeault, Dingwall and De Vries, 2010; Silverman, 2013; Mays and Pope, 2020;). It is not within the scope of this research to explore these ideas in depth or answer some of the complex and evolving debates within these fields. I will therefore, outline my own approach which leans heavily on the work and stance of greater theoretical minds that have come before me, and which acknowledges the flawed nature of any theoretical stand point ultimately adopted.

The MSc qualification I completed, prior to embarking on my PhD, included exploring competing paradigms and philosophical approaches within the field of research. I explored the positivist paradigm, the realist paradigm, and the interpretivist paradigm on multiple occasions. Fairly early in these explorations, I rejected the positivist paradigm on the basis that the complexity of the discharge process and the importance of the input of different perspectives from professionals, carers, and patients, make it difficult to identify one solution or one set of facts aimed at recording a single objective reality (Bowling, 2014, p. 136; Mays and Pope, 2020). Further to this, the positivist focus on finding truths that are objective and value free (Mays and Pope, 2000, p. 20; Fallon, 2016) was at odds with my interest in carer and patient experience and wellbeing as a subjective concept. Interpretivism, by contrast to positivism, has a relativist ontology (an assumption that reality is subjective) and a subjectivist epistemology (the researcher is part of the investigation, ultimately influences all findings and values the viewpoint of those being studied) (Bourgeault, Dingwall and De Vries, 2010; Mays and Pope, 2000, p. 20). Whilst positivism and interpretivism stand at opposing ends of the ontological and epistemological debate, most researcher's approach, and paradigm fall somewhere between the two.

I was inherently drawn to social constructionism, a key epistemological approach in qualitative research which is not without controversy. I tentatively explored the tenets of critical realism and symbolic interactionism. I ultimately rejected the critical realist ontology as I found the concept of stratified layers of reality, and the search for causal mechanisms and powers at odds with my desire to listen to the perspectives of professionals and carers and value their experiences (Bhaskar, 1978; Archer *et al.*, 2013;). Although critical realism allows for the agency of the individual, in conjunction with causal mechanisms, I felt the search for invisible drivers of behaviour inherently dismissive of individuals who offer to share their knowledge and insights (Archer *et al.*, 2013). I am also unconvinced that all behaviour and actions are necessarily explained by invisible mechanisms which are somewhat unknowable, and I didn't want to focus my analysis on developing theories related to unseen forces driving processes and actions. I attempted to think about the research project from a critical realist perspective and found that the project became driven by the requirement to identify mechanisms and examples of agency, rather than focusing on the discharge process and the unique insights and knowledge of individuals.

Symbolic interactionism’s prioritisation of the individual appealed to me early in the research process (Mead, 1934; Blumer, 1969; Denzin, 1992). However, its overt focus on the individual, and dismissal of the impact of the social structure, ensures that the context of the NHS and social care services become secondary to individual interpretation. Small scale interaction is undoubtably vital in the context of my research project; however, the wider health and social care structure are integral to the focus of the research project. The lack of attention to wider social structures entails that inequalities and power dynamics are overlooked within symbolic interactionism. Such an approach would be unforgivable for a research project exploring a process set within a hieratical organisation, such as the NHS, which wields immense power over people’s daily lives. The medical hierarchy is well established theoretically and experienced practically by individuals. Ignoring these dynamics would not have served the project well.

4.2.4 Social constructionist ontology

Social constructionism first emerged from the work of Durkheim (1897) and the concept that there were a set of normative beliefs, accepted by modern societies, that govern the day-to-day behaviour of human beings. This epistemological approach suggests that meanings within society arise from shared human interactions, which in turn are dependent on and reinforced by further interactions (Harding and Palfrey, 1997). Language is particularly central to this process as it is through language that humans communicate meaning and create power structures, particularly around inherent hierarchies, such as legal and medical systems (Derrida, 1970; Foucault, 1973). This paradigm argues that although there is an objective reality upon which science is based upon, it is experienced and interpreted at a subjective level by individuals. For Eisenberg (2009) this leads to the conclusion that there is no universal truth, even in the medical sciences. Instead, belief systems adopted by society and reinforced by institutions, always influence behaviour and medical explanations. This can help explain differences in understanding, behaviour, culture, and opinion, as there is always a multiplicity of different experiences available to the individual, and different belief systems will influence both understanding of and response to events.

Further to this, Berger and Luckmann (1991) argued that subjective meanings often become objectified over time and become part of a shared common world, internalised by individuals, and reinforced by institutions. This is described as ‘an ongoing dialectical process of externalisation, objectification and internalisation’ (Berger and Luckmann, 1991, p. 149). This approach can be useful in understanding institutions, organisations, professional behaviour, and roles, particularly within established institutions such as the NHS or local authorities.

Several criticisms have been raised against social constructionism, and it has been argued that it becomes trapped in a postmodernist paradigm by reducing reality to language and subjectivism (Harding and Palfrey, 1997). However, these criticisms have been largely addressed by Shotter (1993) who argued that the researcher or individual is part of a social, shared and interactive reality in which social truths can only be discovered by looking at how individuals shape everyday activity, through their interaction within systems. This focus on practices, activities and how procedures are negotiated with others to build shared ideas and meanings, are particularly useful for understanding interactions within the healthcare system between professionals, patients, carers and within institutions, such as in the hospital context. This paradigm allows for the discrepancy between the perspectives and understandings of different health and social care professionals, working in the same context, and patient or carer perspectives. I have outlined in diagrammatical form (figure 6) this experience of reality. This is an allowance integral to my research focus. Figure 6 depicts visually the social constructionist approach.

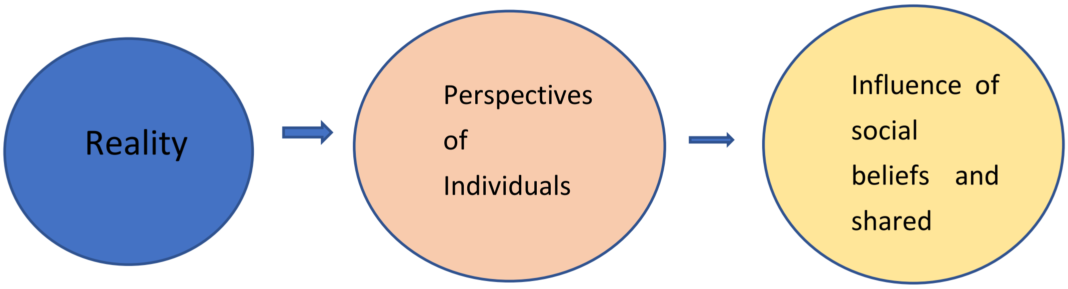


Figure 6. Social constructionism

Social constructionism is a particularly useful ontology for understanding health and social care practice in relation to people living with dementia. This is due to the ways in which ideas around the dissolution of identity, and the eradication of the self for this patient group, have historically been accepted and normalised by both the medical profession and wider society (Sabat and Harré, 1992). The medical model of dementia and its ability to stigmatise the individual has been identified by numerous academics (Sabat and Harré, 1992; Kitwood, 1997), and only recently have these discourses begun to be challenged in both academic discussion and health and social care practice and policy.

In accordance with this approach, the concept of wellbeing has been acknowledged as a subjective notion (La Placa, McNaught and Knight, 2013) with different meanings available in different contexts. Therefore, the factors that ensure wellbeing will have elements of subjectivity for individual patients, and their carers, dependent on their specific needs and circumstances. This has been acknowledged in both academia and health and social care practice, as person centred, individualised care has been adopted as the primary method of interacting with people living with dementia in health and social care contexts (Kitwood, 1997).

4.2.5 Why reject a grounded theory approach?

It is evident from the arguments above that the adoption of a social constructionist ontology allowed me to accommodate a divergence of perspectives, belief systems and behaviour of patients, carers and health and social care professionals within the context of the health and social care system. After deciding to adopt a socialist constructionist ontology, I considered the potential benefits of adopting a grounded theory approach (Glaser and Strauss, 1967; Corbin and Strauss, 2008). I was familiar with the approach having utilised its method on a previous research project. I knew that social constructionism and grounded theory were well suited in terms of epistemology (Charmaz, 2006), and that grounded theory has a well-established place within health research (Mills, Bonner and Francis, 2006; Ralph, Birks and Chapman, 2015). However, my decision to undertake a systematic review at the outset of the research project felt at odds with the spirit and established initial approach of grounded theory. I was also coming to the project with a nursing background and previous experience as a researcher in the field of dementia. Furthermore, my decision to utilise patient and public participation at the outset of the project, and in the design of the interview schedules, did not align with the method of grounded theory (Glaser and Strauss, 1967; Ralph, Birks and Chapman, 2015). Ultimately, I decided that the project didn't align with a grounded theory approach and as the research project evolved in response to the pandemic, I felt this decision to be justified due to the adaptation of the project to pandemic circumstances that would not have adhered to the grounded theory method.

4.2.6 Appreciative Inquiry Approach

I decided to adopt an Appreciative Inquiry approach after reading about the benefits such an approach can bring to a study designed to explore and appreciate the mechanisms of a large organisation, and what changes might lead to improvement (Bushe, 2011; Cooperrider and Fry, 2020). Appreciative Inquiry involves a positive outlook cycle of appreciation and change (Bushe, 2011). The approach aims to identify what works well in an organisation and use these strengths as a springboard for further improvements. The Appreciative Inquiry approach (Bushe, 2007) acknowledges that large organisations are best understood by the individuals that work with and for them, and that you cannot improve an organisation by looking at previous actions, but only by asking what future changes could enhance services, processes, and organisational structures (Cooperrider and Whitney, 2005). It involves a five-stage process and I decided to use the first four stages to support the research project. Definition, discovery, dream, and design were incorporated into the method of the research project which aims to: 'define' wellbeing for carers and health and social care professionals; 'discover' the perspectives and experiences of this population of the hospital discharge process; and asks them to 'dream' of improvements to the overall process. My ultimate role is to begin the process of 'designing' improvements within this thesis and in future research outputs. The 'destiny' (sometimes referred to as delivery) aspect of the cycle, where positive changes are implemented in practice and policy, will take place outside of the scope of the thesis and through the implementation of future collaborative research projects.

This approach positions carers, and health and social care professionals, as best placed to advise or ‘dream’ of improvements to the hospital discharge process due to their specialist experiences, acumen and knowledge. Furthermore, the open nature of the change process allows for the design and destiny/delivery aspects of the research project to be achieved outside of the thesis, and in conjunction with health and social care partners in an un-prescriptive format. Additionally, the Appreciative Inquiry approach aligns neatly with the social constructionist paradigm, as it accepts that institutions and organisations are formed by their participants, and able to enact change as fluid, constructed entities through human action (Cooperrider and Whitney, 2005).

In this research project, I have adopted the Appreciative Inquiry approach as a theoretical perspective and guiding influence (Cooperrider and Fry, 2020). This was particularly pertinent after identifying in the systematic review that there was a research gap in relation to positive discharge experiences. The decision to identify what is currently working well within the discharge process to support the wellbeing of people living with dementia and their carers guided the focus of the project, data collection, analysis process and development of a framework.

Appreciative Inquiry’s ability to identify and build upon a processes’ strengths was appropriate for answering the research questions: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?* I will identify throughout the thesis the times when I was guided by the Appreciative Inquiry approach (Cooperrider and Fry, 2020) in designing the interview topic guides, analysing the data and developing the framework. The Appreciative Inquiry process is depicted in figure 7.

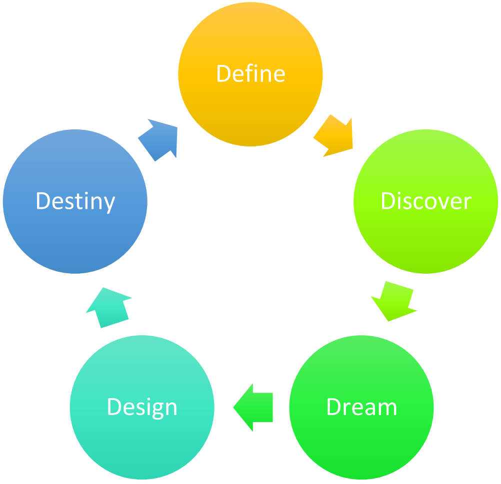


Figure 7. Appreciative Inquiry cycle (Cooperrider and Whitney, 2005)

4.3 The qualitative method

4.3.1 The ethnographic and interview method

Once I decided to adopt a social constructionist paradigm utilising the Appreciative Inquiry approach, I turned to consider the most appropriate qualitative method or methods to adopt. I chose to adopt a flexible case study design (Yin, 2012) because of this method's ability to enable the study of a phenomena in context, and to account for a discharge process that can be messy with blurred boundaries. The 'case' boundaries of my research project are broader than the usual case study unit. This non-conventional format was necessitated by the nature of the pandemic, and the inability to access settings in the usual manner of a qualitative research study. In identifying my research as a case study, I heeded the work of Yazan (2015) who explored the juxtaposing approaches of different theorists to the case study format, and ultimately adopted the approach of Merriam (1998, p. 148), who describes "an intensive, holistic description and analysis of a bounded phenomenon such as a program, an institution, a person, a process, or a social unit". The case study in my research is the integration of the discharge process and the process of the impact of the pandemic regulations. The period in which the research project took place is unique. In 2020 and 2021 the process of hospital discharge was markedly different to the situation in 2019 and 2022, when the impact of the pandemic and pandemic regulations either did not exist or were regulated to a more minor consideration. If I implemented the same research project today, the data collected would be significantly different due to the abatement of the pandemic. On reflection, I have come to understand this modified case study as a neo-case study which fits the requirements of this specific period. The case study method's ability to identify explanatory aspects of the hospital discharge process, a process that is extremely complicated in its many characteristics, appeared ideal to enable the exploration of the breadth of the process, from the hospital to the community setting, during this unique period (Creswell and Poth, 2018).

I chose the ethnographic and interview method as this combination has many identified benefits. Implementing both interviews and an ethnography allows the weaknesses of the individual methods to be addressed by the strengths of the complimentary method. In healthcare research, the interview method can help researchers access the opinions and beliefs of individual patients concerning their treatment or subjective healthcare experience (Seale, 2012). However, in critique of the interview method theorists operating within a positivist framework have identified the possibility of the researcher distorting the interview data through misleading or biased questions (McCracken, 1988; Alshenqeeti, 2014). This criticism is of limited applicability to the ontology of this project. Another issue is the reliability of data derived from the interview. Theorists researching within a constructionist perspective have argued that there is no route within the interview process to access the thoughts or experiences of participants, only co-constructed narratives (Silverman, 2017). Interviews are characterised as merely reflections of 'cultural convention' (Denzin and Lincoln, 2018).

The ethnographic method, used in conjunction with interviews, allows this criticism to be addressed. Ethnography can allow researchers to fill the contextual spaces left by interviews and quantitative research. This is achieved by allowing 'social processes observed and […] social meanings,' to be identified in context (Hammersley, 1992). Ethnography can also identify discrepancies between actions discussed in interviews and observed behaviours (Agar, 1996). Further to this, ethnography can answer the criticism that interview data is a construction devised between the interviewee and interviewer (Rapley, 2001). However, ethnography has been similarly criticised (Clifford *et al.*) as being a construction of the ethnographer alone. Therefore, it is open to researcher bias, misunderstanding and fabrication (Agar, 1996; Jones and Smith, 2017). However, Hammersley (1992) and Rashid, Caine and Goez (2015) have answered these criticisms. The use of a research diary and explicit statements, detailing both the research context and areas of potential bias on the part of the ethnographer, are identified as removing these obstacles.

I decided that combining the ethnographic and interview method would allow me to address the research aim and objective effectively. Interviews with carers and health and social care professionals would allow for insights into their perspectives concerning the factors that ensure wellbeing during the discharge process. I identified that some people living with dementia would be unable to take part in interviews and that the ethnographic method would facilitate their inclusion in the data. The ethnographic method also allows the observation of the discharge process in real time, and for the actions and behaviour of carers, patients, and staff to be viewed in context. Combining these two methods would create a comprehensive and detailed overview of the hospital discharge process, and the holistic factors that ensure wellbeing is maintained for this patient and carer group.

However, along with the global qualitative researcher population, I was compelled to adopt other measures due to the restrictions associated with the COVID-19 pandemic. Social distancing created barriers to traditional qualitative methods and provided new opportunities. My decision to adopt a case study approach was validated as the wide-ranging impact of COVID-19, and the public health measures adopted in response, meant that my research findings became partly about the experience of individuals living with dementia, and their carers, of the hospital discharge process during the COVID 19 pandemic. Reflecting this unique set of circumstances was supported by the flexibility and context specific focus of the case study method (Merriam, 1998; Yin, 2012; Creswell and Poth, 2018) which allowed the impact of the pandemic to become part of the case studied.

4.3.2 The impact of COVID 19 on the methods utilised.

At the end of my maternity leave and as I returned to the research study, I began the process of changing the focus of my PhD to reflect the changes occurring throughout society in response to the COVID-19 pandemic. The hospital discharge process itself had been profoundly altered by the guidance issued by the UK Government (Department of Health and Social Care, 2020a). New guidelines prevented visitors, including informal carers, from supporting people living with dementia in the hospital setting. I began to wonder how this would be impacting on the wellbeing of those patients who would usually experience open visiting with their relatives and carers. I also wondered how this would be impacting on carers and relatives used to supporting their relatives daily, and who were suddenly without contact. I speculated about how different health and social care professionals might find their roles altered, and how this might impact their ability to support the wellbeing of patients and carers during social distancing, and particularly in the light of Personal Protective Equipment (PPE) requirements. I felt that I could not ignore the impact that new guidance might have on professional roles and their ability to support patient and carer wellbeing.

I was also aware that the 'meaning' of the NHS and the role of health and social care professionals within the minds of the public, and the media had changed. The 'clap for the NHS' was a focal point of the English lockdown and the much-maligned NHS underwent a transformation in image. Further to this, the focus on shielding the clinically vulnerable, particularly the older section of the population, raised the profile of areas of the population often ignored by the media, including carers and people living with dementia. The media scandal regarding the Government's decision to discharge patients to care homes without receiving a COVID 19 test, and the subsequent large number of tragic deaths, highlighted this population and the vital role played by the hospital discharge process. These changes in 'meaning' have continued throughout the pandemic and, as I write this on 'Freedom Day' July 19th, 2021, the importance of the vulnerable population has once again shifted to being of secondary concern as society irreversibly 're-opens,' and COVID 19 infection numbers soar. The imagery utilised by the UK government during the corona virus pandemic continued to shift and morph as social meaning and understanding changed. As I further edit this thesis in March 2023, it is difficult to recall this period fully, as the pandemic has been largely consigned to a concern of the past.

The images below typify the ‘branding’ of the pandemic to the population at large from a terrifying and dangerous illness to a minor threat.

Figure 8 depicts the early pandemic images.

Figure 8. Stay Home, protect the NHS, save lives. April 2020

Figure 9 is a visual depiction from later in the pandemic representing the change in approach and visual narrative.

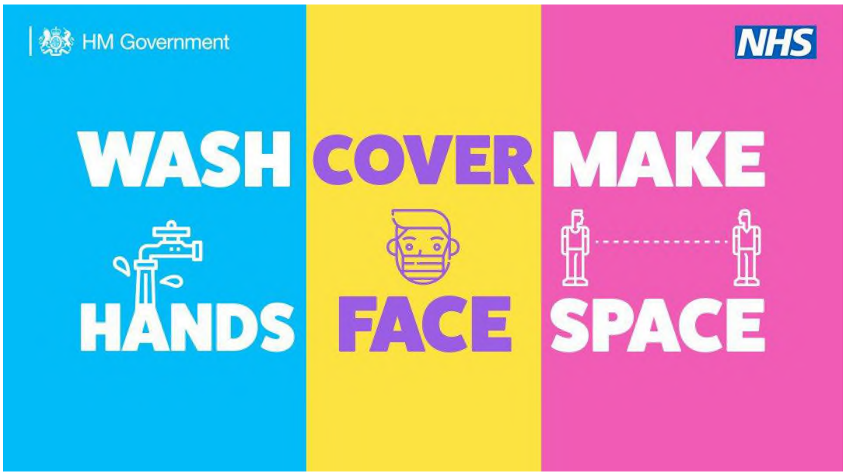


Figure 9. Hands face space. August 2021

These continuous changes in meaning bolstered my decision to adopt a social constructionist ontology. The hospital discharge process altered both practically and in relation to social meaning. No longer just a way to ‘empty hospital beds,’ as it had been previously characterised, the importance of robust planning, the focus on safety, and the importance of prioritising the person being discharged from hospital, and their family, were evident. The process, which has often been overlooked as an addendum to the important medical treatment occurring within the hospital, was revealed as potentially the most important aspect of the hospital stay and not the afterthought.

I realised that all these changes would radically alter the nature of my fieldwork and ultimately my thesis. I accepted that an ethnographic study would not be possible within the contextual period of my PhD. I began to explore alternative methods for achieving the aims of my research project within the time frame of the PhD. I decide that the scope of the research project would need to incorporate the impact of COVID 19 measures on the discharge process, and the legacy that the measures would have in order for the findings of the research project to be relevant, and valid, in the ongoing pandemic and post-pandemic period.

4.3.3 Online interviews and the digital 'field'

I began researching the option of virtual interviews via mediums such as Teams, Zoom and Starleaf, alongside telephone interviews. I had limited understanding of these methods and found the published literature available very restricted. There was an established body of research pertaining to telephone interviews (Sturges and Hanrahan, 2004; Novick, 2008; Holt, 2010; Irvine, 2011; Irvine, Drew and Sainsbury, 2012; Drabble *et al.*, 2015; Fischer *et al.*, 2015) but significantly less literature available in relation to interviews via digital means. The technology to support video calling was available pre-pandemic but only used by professionals in very limited circumstances. Skype, WhatsApp, or Facetime were the dominant mediums used and for most of the population these methods were not a key part of their daily communication with others.

The uptake of digital means of communication, facilitated by lockdown and isolation measures, enabled the option of digital interviews to be considered. The unknowns and potential pitfalls of using the digital medium were outweighed by the ability to facilitate interviews in a context where face to face interaction was not possible. The technology to facilitate interviews developed significantly during the life of the research project. The mediums of Zoom and Teams became more robust as they were used more frequently in the population's work and home life. Using these technologies for interview purposes presented me with a learning curve experienced by all researchers who turned to these mediums during the pandemic. Significant time was spent learning how to operate the different mediums and schedule recordings and transcriptions. At one point, an amendment to the study had to be submitted as I had not realised the recording possibilities of Teams and wished to use this medium.

The available literature detailing the impact on the data of using these mediums was limited. When I was designing my study in May 2020, articles pertaining to interviews carried out online were largely limited to discussions around the use of Skype (Cater, 2011; Hanna, 2012; Deakin and Wakefield, 2014; Seitz, 2015; Lo Iacono, Symonds and Brown, 2016), and the bonuses and drawbacks of this earlier technological interface. As outlined above, the decision to use online mediums was not driven by theory or findings from other research projects but by necessity. Over the next section, I will discuss why I have come to believe that digital interviews, via a medium such as Zooms or Teams, are equal in value and even arguably superior to face- to- face interviews, which have traditionally been considered the gold standard in qualitative interviewing (Deakin and Wakefield, 2014). I will also discuss the benefits of telephone interviewing, a medium which I found immensely rich and dynamic.

Interviewing via digital means opens new possibilities (Lo Iacono, Symonds and Brown, 2016). The potential of digital mediums, such as Zoom and Teams, for wider and more diverse recruitment has been previously appreciated along with the potential to exclude individuals without the technological know-how or access (Cater, 2011; Jenner and Myers, 2019). This was sadly the case for myself as individuals with dementia often find it challenging to make sense of screen-based technologies, and the ethics of assessing capacity via a digital medium are questionable (Deakin and Wakefield, 2014). I decided early in my assessment of online interview mediums that no interviews with individuals with dementia would be possible. This is a serious criticism of online methods as it could be argued that they are discriminatory, and where possible, face- to- face interviews should go ahead to prevent the impact of digital inequality.

Another drawback of the online interview includes the presence of technical issues connected to working the technology and obtaining sufficient broadband width (Seitz, 2015; Archibald *et al.*, 2019; Howlett, 2021;). Technical aspects can be challenging for both the researcher and the participant who must master these mediums effectively. I spent a significant amount of time learning the technical differences between Teams and Zoom and how to function across both platforms. As many other researchers have, I found many technical issues were overcome easily with sufficient forward planning (Jenner and Myers, 2019). I identified that the ability to record interviews easily, re-watch them at the touch of a button, and create full transcripts instantly was of significant benefit. Transcripts produced often require significant editing but are still an efficient way of recording the dialogue of an interview. Being able to re-watch an interview, phrase or segment instantly was extremely useful during the analysis period. I was able to forward the video to the moment analysed and watch back the interviewee's response. Furthermore, I was able to assess my own interviewing technique. This was often a painful process, but ultimately a valuable one and a learning opportunity.

These benefits are balanced by the reality that concerns about data protection often exist in the online context (Howlett, 2021). The use of online mediums leads to sharing data/personal information with a company, such as Microsoft, as part of the process. However, I found that everyone I contacted who chose to use platforms, such as Zoom or Teams, already had an account and was already choosing to share their video calls with these mediums. The ease of being able to schedule an interview was fantastic and this has been widely recognised previously (Cater, 2011; Archibald et al., 2019; Jenner and Myers, 2019). I did not have to concern myself with interview spaces or travel, vital during lockdown periods, and this allowed participants to simply take an hour from their day to take part.

Loss or lack of rapport has often been cited an issue arising from the online interview (Seitz, 2015; Weller, 2015; Lo Iacono, Symonds and Brown, 2016), but this was not something I experienced during my interviews. I hypothesise that the stilted rapport finding could be linked to an earlier Skype context before the general population were familiar with online video calling. A number of recent articles have reported that rapport has not been an issue while using Zoom. I, therefore, suspect this may be an outdated criticism (Deakin and Wakefield, 2014; Archibald *et al.*, 2019). Alternatively, it could be that due to the ethical requirement to conduct a detailed consent discussion with carers before the interview took place, alongside my approach of having an informal chat with professionals before scheduling an interview, I developed rapport during these earlier conversations and that transferred to the interview itself.

A number of researchers have identified that some participants prefer the online interview for a multitude of reasons (Archibald *et al.*, 2019). Howlett (2021) has discussed the ability of the online interview to re-set the power dynamic of the researcher- participant relationship and place the participant in a powerful position. I agree with this assessment, and I believe that the utilitarian nature of the video call has the potential to ensure that participants maintain dignity and agency during the research process.

Table 7. Online interviews benefits and drawbacks

Table 7	
Organisational ease (geographical and temporal)	Potential discrimination including access to technology, vulnerable groups
Development of rapport	Loss of rapport
Depth of interview	Potential loss of depth of interview
Technological benefits	Issues with technology

In the preceding section, I outlined the challenges but also benefits of the online interview and they are delineated in Table 7. I would like to address some of the criticisms of the telephone interview, a medium chosen by several of my participants. I empowered participants to choose the medium they preferred for the interview (video or telephone), to ensure their comfort. I was sceptical of the utility of the telephone interview in comparison to the online video interview. However, in contrast to other researchers (Irvine, 2011; Irvine, Drew and Sainsbury, 2012; Rowley, 2012), I found no issues with the depth or length of the interview or in the building of rapport. I found that the removal of the face-to-face element added anonymity to the phone call which led to in depth conversations lasting more than an hour.

It has been previously identified that telephone interviews lack the contextual depth of the face-to-face interview due to the absence of body language (Jenner and Myers, 2019). However, I found it easy to identify emotion via tone and subject matter. There were occasions when I did have to ask additional questions to safeguard a participant, as it was difficult to determine if a participant was making an offhand comment or genuinely distressed. I must admit that some of the richness of the data that would have been offered via a video interview was lost in the telephone interview. It could be argued that telephone interviews do not offer as robust a safeguarding framework. This is an important consideration when interviewing participants about emotive subjects.

I decided to implement two separate studies using telephone and online interviews. One study involved interviewing carers about their experiences of the hospital discharge process and the support available to enable and support patient and carer wellbeing. The other study focused on the views and opinions of health and social care professionals regarding supporting carer and patient wellbeing during the discharge process.

4.3.4 Sensitive interviewing

Health and social care professionals were often passionate about their practice and ensuring positive experiences of the discharge process for people living with dementia and their carers. However, their manner of conversation would often be impartial and objective. Interviews with carers were very different. Some carers had experienced very poor care for their relative both in the hospital setting and during the discharge process. Some carers expressed significant grief and guilt due to their experiences of trying to navigate the health and social care system. I discovered very early in the interview process that even consent discussions could become emotional.

One of the ways I navigated this was by empowering participants to choose the medium and steer the main discussion points of the interview. I devised questions in the manner of a semi-structured interview (an example of the topic guide for carer interviews is available in Chapter 14), but I made it clear to participants that the interview would focus on what they believed was important about their experiences and would only cover topics they were comfortable to discuss and believed were vital for understanding their experiences. I utilised a topic guide as a prompt but allowed the participant to direct the conversation.

The benefit of the semi-structured interview is that it provides a guide to the interview procedure, and allows for greater comparability (Barriball and While, 1994) between participant answers. The flexibility to change the question format, order and focus, according to the needs of the interview participant (Kallio *et al.*, 2016), was a useful attribute during the interviews themselves. As the interview developed, I would refer back to the topic guide and probe the participant in relation to follow up subjects.

I drew on the literature available regarding the process of sensitive interviewing and utilised the findings of other researchers to guide my approach to the interview process. Foremost, the importance of demonstrating empathetic and sensitive questioning was vital to my interview technique (Dickson-Swift *et al.*, 2007; Elmir *et al.*, 2011). I asked questions in an open manner that allowed participants to answer according to their preference, for example, ‘can you tell me about your recent experience of when your relative left hospital.’ I allowed participants to talk about their mental health and wellbeing, but I didn’t probe if they indicated high levels of distress concerning a topic. Sometimes I asked questions in an indirect manner to allow participants to choose what to reveal, for example, ‘So you find X is a good source of support?’

I was aware of the importance of creating a safe and comfortable environment for the interviews to take place (McCosker, Barnard and Gerber, 2001; Elmir *et al.*, 2011). The subject matter discussed could be extremely sensitive. Participants had often experienced the bereavement of a parent or been involved in the decision to admit a parent to a care home. Several participants expressed guilt associated with decisions made and ongoing feelings of grief and depression. The consent discussions I held with participants allowed me to develop a rapport (Elmir *et al.*, 2011) prior to the interview, and I determined that this created a more comfortable environment during the interview. I utilised the principles of reciprocity to further create a secure environment and build empathy and understanding between myself and the participant (Booth and Booth, 1994; Corbin and Morse, 2003).

I often shared details of my own experiences to ensure that the participant was not in a position where they always gave and I always took, without some equality in the relationship. This is an approach that has been documented as integral to the development of trust within the interviewer/participant dyad. The sharing of information by the interviewer has been characterised as vital to ensuring equity within the interview space (DiCicco-Bloom and Crabtree, 2006). At the close of the interview, I used the empathetic skills developed as a staff nurse to assess the level of distress visible in participants. I often checked what their plans were for the rest of the day and that they would not be alone. I checked in with participants at some point after the interview to return a copy of the consent form to them and ensure that they were not too distressed by their participation.

4.4 Value, quality, and reflexivity in the research process

The next section of this chapter will outline the ways in which I engaged with the concepts of validity, reliability and trustworthiness when designing, implementing, and documenting the research project (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2013; Korstjens and Moser, 2018). These terms can be used interchangeability within the qualitative research sphere and are sometimes replaced by concepts of credibility and dependability (Guest, MacQueen and Namey, 2011; Noble and Smith, 2015). Choosing how to engage with these concepts is vital to ensuring the quality of research findings and for allowing other researchers to understand the value of the research product. I also engaged with the importance of ensuring rigour by explicitly outlining my method and approach early within the research design to guarantee clarity (Mays and Pope, 1995).

4.4.1 PPI (Patient and Public Involvement)

Modern health and social care research should be relevant and meaningful to the individuals for whom the research is ostensibly implemented (The King's Fund, 2018). The Wanless report (2002) demonstrated the need to ensure that members of the public were highly engaged in the delivery of health and social care services and integral in the design of service provision and research. This is especially true of research in the field of dementia where individual rights, preferences and opinions, have been historically overlooked by health and social care structures (Kitwood, 1997).

Qualitative researchers have recognised the many benefits of including patients and the public in the planning and delivery of research to ensure it is both designed and implemented to reflect the concerns and experiences of key stakeholder groups, including carers and patients (Brett *et al.*, 2014). Correspondingly, the NHS has recognised the value of the input of patients and carers with expert experience in their field. Policy documentation has reflected the need for stakeholder and service user involvement at all levels of research development (NHS England, 2017). Research regulating bodies such as the Health Research Authority (HRA) insist on relevant and meaningful PPI as an integral part of any study seeking HRA approval. During the COVID 19 pandemic, the HRA even adopted a fast-track service to ensure the involvement of relevant members of the public for all proposed research (NHS Research Authority, 2021).

However, PPI is often criticised as tokenistic and a box ticking exercise, with members of the public simply asked to provide feedback or invited to meetings (Minogue et al., 2005; Brett *et al.*, 2014). Furthermore, ensuring genuine and meaningful PPI can be a complicated process as the thoughts and perspectives of participants may differ to the opinions of the research team. The PPI relationship may become strained if the perspectives of all are not respected (Reed, Weiner and Cook, 2004). I recognised the value of PPI early in the design of my research, and the benefit of seeking and respecting the opinions of a wide range of stakeholders, including carers and professionals in health and social care.

I consulted with a small group of carers to listen to their positive and negative experiences of the hospital discharge process and the support available during this process. Listening to their stories and insights helped shape my project's focus on the wellbeing of carers in particular. It was clear that wellbeing was not addressed as a priority during the discharge process. I found the lack of attention to both patient and carer wellbeing during such a difficult and complex process concerning. The carers I spoke to mentioned that the absence of emotional and practical support during the discharge process was a significant problem.

I also consulted with several different professionals during one-on-one meetings including specialist nurses, discharge co-ordinators, and social workers, to ask their opinion of the research topics that would aid their daily practice. These conversations allowed me a broad overview of the acute hospital discharge process and the differing priorities and perspectives of professionals. This enabled me to design the professional interview study to include questions on topics that were important to, and relatable for, professionals and which reflected their daily practice.

Later in the research process, I again consulted with carers regarding the design of the participant information sheets to be used in the recruitment of carers as participants. The feedback to simplify the jargon used in the information sheets, and ensure a more readable layout, helped me to design more accessible documents. Unfortunately, changes in the nature of the research project due to the pandemic, the need to include standardised General Data Protection Regulation statements, and input by the NHS Research Ethics Committee, meant that the final participant information sheets were not as accessible as I would have wished.

4.4.2 Quality in the qualitative research process

The difficulties faced by qualitative researchers when confronted with the quantitative standards of validity, reliability and rigour, have led theorists to explore ways of maintaining quality in qualitative research that does not lead to positivist reductionism but also escapes the criticism of outright relativism (Lincoln and Guba, 1985; Seale, 2002; Horsburgh, 2003). The nature of quality itself is controversial in qualitative research where divergence, context and uniqueness are celebrated, while uniformity and standardisation are rejected (Braun and Clarke, 2013). In health-related research, such as the research project I embarked on, being able to justify any findings or recommendations is crucial to the utility of the research findings and therefore quality, even as a disputed measure, is an important consideration.

At the beginning of my research journey, I examined different ways of ensuring quality in the qualitative research process. It appeared to me that reflexivity (Horsburgh, 2003) would be an integral element in maintaining the value of any findings from the research. My positionality as a nurse, and my background as a researcher in the field of dementia, entailed that the influence of my perspective on the research method, analysis, and findings, would be considerable. Lincoln and Guba (1985) identified that all research findings and theories are the product of the interaction between the researcher and participant and, as such, they are situated in the context and values of the two parties. (Lincoln and Guba, 1985; Sandelowski, 1993; Creswell and Miller, 2000; Silverman, 2013). Therefore, the importance of detailing my assumptions and perspectives and reflecting on how these may influence the methods I used, and the analysis I conducted, was crucial to the research process (Creswell and Miller, 2000). That is not to say that outlining the bias and influences I have will negate their impact on the research findings, but adopting a transparent approach will enable the reader to judge the findings in context. I outline my perspective further in the reflexivity section of this thesis.

The established approach to maintaining the quality of qualitative research was outlined by Lincoln and Guba (1985). This approach which focuses on credibility and trustworthiness aims to lay bare the workings of the research process, and researcher, to ensure clarity in the qualitative process and avoid opaque methods and findings that are difficult for other researchers to evaluate. The ‘authenticity’ of the findings is crucial both in terms of participant and researcher input and the analysis process (Creswell and Poth, 2018). This approach includes member checking, triangulation, exploring deviant cases, transferability, ensuring by re-reading transcripts that findings accurately reflect data, and maintaining transparent audit trails. My research, while constructionist in epistemology and qualitative in method, is aligned with the field of health research. Therefore, maintaining quality and ‘truth’ within the method, analysis and findings is an important consideration (Seale, 2002).

Qualitative research must be transparent in all aspects to enable the actions and thought processes of the researcher to be available to the reader and enable the assessment of the findings of the research.

I originally planned to implement triangulation of method in relation to data collection by combining the ethnographic method with the interview technique (Flick, Kardorff and Steinke, 2004). However, this became unachievable during the pandemic when no one could enter the hospital outside of clinicians and patients. I ultimately adopted a more informal version of triangulation by obtaining interviews with both carers and professionals, reflecting multiple perspectives, and enhancing the overall picture of the hospital discharge process. This softer version of triangulation ensured that the experiences of different sides of the process are visible in the data, allowing for a more nuanced depiction of the discharge process, which reflects the juxtaposition of opinions and viewpoints both lay and professional.

I spoke with professional participants on at least two occasions. Once in the informal discussion and once during the interview. This allowed professional participants time to think over their responses and moderate their thoughts and words before the formal interview process. I believe this has enhanced the quality of the data collected as professional participants were able to think through their perspectives and opinions and re-assess the information they chose to convey. The drawback of this approach was that participants could change how they formulated their answers away from their first reactions. However, I believe that allowing participants time to think about their response is valuable for collecting data that reflects their considered opinion.

The approvals from the NHS dovetailed well with the concept of developing a clear audit trail. Ensuring an audit trail includes the provision of both documentation detailing the actions taken, and the decision making and thought processes of the researcher during the research process (Carcary, 2009). I adopted a research diary which I wrote in every day during my journey as a PhD student. The entries were not always long or concise and the diary itself also contains personal notes and details about my life during this period. The entries often reflect my first thoughts and musings and to-do-lists. This reflects the reality of the qualitative research project and the iterative nature of evolving concepts, ideas and plans. Nothing about my research project remained static, it was in a continuous state of evolution due to the uncertainty of the pandemic, and the adaptations I made to address the limitations, but also possibilities, of the context.

4.4.3 Reflexivity

Engward (2015) outlines some of the challenges of reflexivity, where outlining one's positioning must be balanced with the need to prevent the research becoming solely about the author and their history. Finlay (2000) indicates the importance of outlining bias, perspectives and experiences, to allow the reader to identify the impact on the analysis process and findings. I outlined my personal experiences and positioning at the introduction of this thesis, but I will reflect further at this point in the methods section.

Throughout the research process, I was aware of the impact of my experiences, as a health care professional, on my interpretation of the data. I believe that this led to a rich and full understanding of the discharge process based on my ability to understand the context of participant narratives. However, my understanding of the challenges of the nursing role meant that I was instinctively drawn to validate the perspective of the nursing participants and support their world view, and this must be acknowledged.

As outlined in the opening chapter, I am also, in a limited sense, a carer for my grandfather who is diagnosed with vascular dementia and Alzheimer's disease. I sometimes advise, but more importantly, listen to relatives who are immediate carers to these family members. I am aware of the physical and emotional cost of these roles. Therefore, I believe that I have a comprehensive overview of being both a carer of someone living with dementia, and a health professional. I believe that I am able to maintain a reasonable balance between both perspectives and allow my understanding of both perspectives to further illuminate the context of the findings.

Alvesson and Skolberg (2009) identify four levels of reflexivity that a researcher can employ. The first level is gained by ensuring that they do not dominate the data collection process by asking open questions and allowing participants to guide the topic. I demonstrated the data collection interview technique, and the ways in which I aimed to democratise the process, in the previous section outlining how I employed sensitive interviewing.

During coding, Alvesson and Skolberg (2009) identify that is it important to recognise any data not included in the findings and recognise where there are deviant findings. I outline in the findings section where there are alternative findings to give both a balanced view of the data and prevent the cherry picking of findings that suit my arguments. The third level is obtained through the clarification of the political-ideological environment. Within the introductory chapter I outline many of the ideological approaches underpinning this research project and reflect on this further within the discussion section of this thesis.

Lastly, Alvesson and Skolberg (2009) identify that researchers must be aware of the way they present their research and the words and language chosen. I am explicit concerning the use of the Appreciative Inquiry approach and that many of the linguistic choice are supported by wider literature identified in the systematic review and the person-centred care ethos within this research sphere. I believe that throughout this thesis I have been reflexive in the presentation of data collection and findings, such that the reader may understand my perspective, and its impact on the project conclusions.

4.5 The ethical process

The protection of the rights of participants is one of the most important aspects of any research project (Bourgeault, Dingwall and De Vries, 2010). This is increased where there is ‘institutional vulnerability’ due to being linked, through employment or being a patient or carer, to a large health and social care organisation (Bourgeault, Dingwall and De Vries, 2010, p. 591). In this section, I will outline the complicated process of obtaining the ethical approvals needed for two separate qualitative studies, from the NHS and local hospital Research and Development departments, during a pandemic.

The context of the pandemic entailed that a pragmatic approach had to be taken to the data collection process for this project. The decision to have two separate studies, one including professional participants and one including community-based carers, was due to the limited time available in which to undertake the project, and related concerns regarding feasibility during the English Lockdown periods. It was unknown during the early stages of the pandemic in 2020 which studies would be considered ethical in light of the requirement for remote interviews and remote consent procedures. It was decided to have two separate studies to enable the commencement of data during this period of uncertainty.

4.5.1 Re-designing the protocol and research project documentation. Obtaining approvals

Once I had decided on the medium of digital interviews, the next step was to re-design the protocol and documentation for the research project. I re-visited the research proposal and began the process of re-writing the protocols for the two separate research projects. I decided to adapt the original research project which involved interviews with health and social care professionals and adjust it to suit the digital interview medium. However, I incorporated exploring the impact of COVID 19 on the discharge process into the objectives of the study. The value of the Appreciative Inquiry approach (Priest *et al.*, 2013) was evident during the re-design of the topic guides for the semi-structured interviews (please see Chapter 14 for the carer and professional study protocol). The guides were designed to focus on aspects of the discharge process that supported wellbeing in accordance with the strengths approach (Cooperrider and Whitney, 2005), and to account for the impact of the COVID 19 pandemic.

Being unable to implement an ethnographic study based in the hospital setting due to the impact of COVID 19 was disappointing. I felt the loss of the rich data that such a study would have afforded and the ability to observe hospital discharge processes in person. However, I quickly realised that a unique opportunity to collect data during pandemic conditions had arisen. My experience in many ways echoed the pandemic experience of professionals, patients, carers and relatives, of the hospital discharge process. Face- to- face meetings were not taking place and discussions were occurring over the phone or via digital mediums. Therefore, the method of my research project mirrored the method by which discharges were being organised in the hospital during this period.

I began to appreciate the opportunity to collect data pertaining to the pandemic experience in real time, and the prospect of incorporating the impact of COVID-19 on the discharge experience into my research project. I decided that interviews via phone and digital mediums with the carers of people living with dementia would offer the opportunity to explore the discharge experience, whilst protecting the safety of participants and adhering to social distancing legislation.

I recognised that it would not be possible to conduct interviews with people living with dementia via phone or digital mediums. Touch and face- to- face interactions are vital for capacity assessments and ensuring participant wellbeing during the interview. This would not have been possible via remote methods. The complexities of technology, and the sensory and memory challenges that people living with dementia face, would have made interviews extremely challenging. It would have been unlikely that such interviews would be considered ethically sound. Due to the limited time available for this project, and the uncertainty of the early phases of the pandemic, when drafting the ethical approval application in May 2020 it was not believed that ethical approval would be given for a remote methods project which included people living with dementia. This is due to the capacity assessment that is required from NHS research ethics committees. I was not certain that an online study, with a remote consent protocol, would be granted approval during this time. Later in the pandemic, it became apparent that ethical approval would be granted for studies taking place remotely, but this was not known in early 2020 when technologies, such as Zoom and Teams, were only beginning to be understood and used in the research context.

Further to this, it would not have been ethical to ask people living with dementia to recall a historical period when they were in hospital and very unwell. Due to the topic of hospital discharge, it was likely that people living with dementia would have been too unwell to be included via digital means. Many of the carers that I interviewed noted that the person they cared for had been very unwell with COVID-19, and several individuals had died in the period before the interview. One potential carer participant withdrew from the study as the person living with dementia began to die during the hospital discharge process itself. Some of the individuals living with dementia had become residents of care homes following their hospital admission. It would not have been possible to access individuals living in care homes during this period. Relatives themselves found it impossible to access their loved ones. It would not have been ethical or feasible to include unwell people living with dementia in this study during this period.

The loss of the voices of people living with dementia is a significant absence within the research project. The ethnographic observations and potential interviews would have incorporated their voices into the data collected. This meant that the data collected became primarily about the experiences of health and social care professionals, carers and family members, and their perspectives of the discharge process for people living with dementia. This limitation is acknowledged throughout the thesis and is an unavoidable consequence of the COVID 19 pandemic on the data available for collection. However, the loss of such voices enabled the research project to focus more thoroughly on the experience of carers during this period. It leaves scope for future research projects to explore the topic with people living with dementia exclusively, preventing such a project from being distracted by carer input.

It was difficult to access many of the professionals involve in the discharge process during this period due to the pressures that the NHS were experiencing. Interviews were regularly cancelled due to the absence of colleagues or workloads being too high. Accessing spousal carers was also difficult due to the inability of carers to access any respite which would have allowed them to take part in an interview. Interviews took place sometimes with the person living with dementia asleep in another room or in the same room with the carer breaking away from the interview to provide care at times.

I applied to the HRA for approval for the re-designed protocol and documentation for the interview study involving health and social care professionals. I also applied for a letter of access and approval from the Research and Design (R&D) department at Newcastle Upon Tyne Hospitals NHS Foundation Trust. Embarking on this task remotely was challenging and involved many hours emailing different departments and individuals to identify the required steps to complete the task. I received HRA approval in

September 2020 and R&D approval in October 2020, alongside the required letter of access. I submitted an amendment to the research project in January 2021, after finding that I had omitted to include visual recording of interviews via Teams to the original consent form, and participant information sheet. University ethical approval was issued in September 2020 due to the low risk of the research project.

4.5.2 Research Ethics Committee approval

I identified that the study involving interviews with carers and volunteers required a proportionate review from an NHS Research Ethics (REC) Committee. I submitted the application in October 2020 and attended a Zoom qualitative REC meeting in November 2020. The REC decided that although the study was eligible for a proportionate review, they requested attendance at a full REC meeting. The REC delivered a provisional favourable opinion in November 2020 but required further transparency around GDPR, student sources of support and consent discussions.

Further to this, documentation was revised, and I developed a distress protocol and confidentiality protocol as requested by the REC. These were welcome additions to the protections available to participants which were built into the study. As a novice researcher, they gave me a road map of the actions necessary to protect both myself and my participants. I remain grateful to the REC for their input as I found their additions to the study helpful and supportive when faced with distressed participants during the data collection period. In February of 2021, the final favourable opinion was received. Ultimately, the involvement of the REC ensured that the final study was ethically robust and designed to support the wellbeing of all participants.

4.6 Data collection

4.6.1 Interview period

Data collection took place between December 2020 and October 2021. Participants were interviewed via telephone, Teams or Zoom, and transcripts were produced via Teams, Zoom or from recordings. When interviewing professionals, informal conversations took place before the interviews. All discussions and interviews took place via Teams and Zoom. This had a subsequent impact on the data collected during the formal interviews, as I had loosely discussed the topics explored in the interview previously. Health and social care professionals often responded in different ways to questions asked during the interview itself, in comparison to when the topics were covered in earlier discussions. As mentioned earlier in this chapter, I believe that there was a positive impact of these earlier discussions, as they ensured that professionals had considered their responses to the questions asked. However, some might criticise this by suggesting that professionals could self- edit their responses. This criticism is predicated on the concept that a first answer is the most reflective of an opinion or perspective. In response to this, research has shown that serial or multiple interviews tend to enable a more reflective and comprehensive set of responses to set questions (Carter *et al.*, 2018).

Carer participants often preferred telephone interviews to Zoom interviews and completed a consent discussion in advance of the interview. Due to the delay in NHS research ethical committee approval, professional interviews commenced before carer interviews. The first phase of the data collection took place during the second national lockdown in England in 2021. It was a challenging environment in which to recruit busy and stressed NHS and social care professionals, who were often juggling short staffing situations, and high patient numbers. It was also a challenging environment for carers who were without respite, and many were unable to take part in interviews. The majority of carer interviews took place after the easing of social distancing measures in the summer of 2021, when carers were able to find respite in the community and had the ability to take part in research.

4.6.2 Recruitment

I recruited participants in very different ways across the two studies due to the different ethical approvals and regulations in place. I began recruiting health and social care professionals via my professional network and ultimately via the CRN (clinical research network). I began recruitment of participants by contacting professionals I had met via conferences and dementia policy groups. I connected with several different CRN groups who supported me to reach a wider pool of potential participants across different NHS Trusts in England.

The process of recruiting professionals remotely via email, news bulletin, and the NHS intranet, during a pandemic was challenging. Many professionals were time poor due to staff sickness, isolation policies, and burnout, following the many months of the pandemic. Organising a suitable time for an interview was tricky. I was, and I am, extremely grateful for the time the individuals in this research study gave me during a very difficult period in their professional lives.

Recruiting carer participants during the height of the pandemic proved at times almost impossible. In the qualitative research handbook, *Doing Qualitative Research* (Silverman, 2013, p. 216), there is a section detailing a PhD student's struggles to recruit participants in an international setting. This student faced a vast array of recruitment hurdles including local research councils, travel disruptions, and language barriers. Silverman's commentary is that this is a nightmare scenario that would be unlikely for the average PhD student. However, 2020 re-wrote the rule book on difficult participant recruitment environments. The ongoing uncertainty around travel and access, the UK lockdown hokey cokey, the profound impact on carers and other vulnerable groups of long-term isolation and lack of social support, alongside issues around burnout and sickness within the NHS, and social care sector created a hostile recruitment environment.

I began recruiting carers via voluntary community groups and Facebook posts. I also attempted to recruit participants via local council websites and newsletters. It was a difficult process as most carers were exhausted from the ongoing strain of the pandemic and the absence of respite and community support. I eventually connected with an Admiral Nurse based in the community who referred me to a network of carers who had experienced the hospital discharge process and were keen to be involved in the research project.

The recruitment process for carers involved a consent discussion being held separately to the interview to ensure that the participant understood what taking part in the research involved. When I reflect back on the recruitment process, there were a lot of false starts and hours spent speaking to individuals who ultimately decided not to be involved, or who could not aid me in recruitment further. It was a very labour intensive and grinding process for me as a novice researcher who was feeling fatigued and lacking in respite due to caring for a toddler during a pandemic. However, I recognise that my experience as a researcher reflects the experience of my participants, and of many people within the UK during the corona virus pandemic, when respite was withheld in the workplace and at home to limit the spread of the virus.

4.6.3 Sampling

I intended to utilise purposive (Coyne, 1997) sampling to identify individuals with the necessary experiences to provide rich, qualitative data. Due to pandemic conditions, I had to sample individuals who had the time, capacity, and interest in being involved in the research. I aimed to include a broad sample of carers that reflected the diversity naturally evident in the carer population. I did not specifically target male or female carers or any specific age group or experience range. In relation to health and social care professionals, I aimed to recruit a wide variety of roles and professions to ensure a full picture of the discharge process. However, the significant pressure that the NHS and social care system was under meant that I had to interview professionals who could find the time to speak to me in a very difficult working climate.

Carer participants included sons, daughters, daughters-in-law, spouses, a granddaughter, and a niece. I interviewed 14 carers and transcribed 13 hours and two minutes of data. 10 carers opted to take part via video interview, four carers chose to take part in a telephone interview. Table 8 includes the details of professional and carer participants. Table 9 contains further details regarding the length and reason behind the hospital stay. Please note that the name of each carer included has been anonymised to protect participant confidentiality. All carer participants were based in the UK and all professionals were working for the NHS, Local Authority or had significant experience of working within and with the NHS. The professional participants have been given a number to differentiate their input.

Table 8. Participant details regarding interviews.

Table 8				
Carer interviewee and location	**Relationship**	**Interview length and method**	**Professional Interviewee and location**	**Interview length and method**
Carol (Northwest)	Daughter in law	1 hour 12 mins Video (Zoom)	Nurse 01 (Northeast)	45 minutes Video (Zoom)
Louise (Northwest)	Volunteer and daughter	27 minutes Video (Zoom)	Specialist Dementia Nurse 4 (Southeast)	23 minutes Video (Teams)
Michael (Northeast)	Son	19 minutes Video (Zoom)	Specialist Dementia Nurse 3 (Southeast)	1 hour 5 minutes Video (Teams)
Shelly (Northeast)	Daughter	1 hour 11 mins Phone	Specialist Dementia Nurses 6 and 7 (Joint Interview)	1 hour 10 mins Video (Teams)
Katie (Northeast)	Daughter	1 hour 50 minutes Phone	Specialist Dementia Nurse 2 (Southeast)	32 minutes Video (Teams)
Elizabeth (Southeast)	Wife	55 minutes Video (Zoom)	Occupational Therapist 01 (Southeast)	29 minutes Video (Teams)
Harriet (Northeast)	Niece	1 hour 10 minutes Video (Zoom)	Physiotherapist 01 (Northeast)	37 minutes Video (Teams)
Jane (Northeast)	Granddaughter	1 hour 20 mins Video (Zoom)	Specialist Dementia Nurse 5 (Northeast)	33 minutes Video (Teams)
Abdul (Midlands)	Son	45 minutes Video (Zoom)	Social Worker 01 (Northeast)	35 minutes Video (Teams)

Faizal (Southeast)	Son	49 minutes Phone	Consultant 01 (Northeast)	43 mins Video (Teams)
Amy (Northeast)	Daughter	1 hour 16 minutes Phone		
James (Northeast)	Son	1 hour and 2 minutes Video (Zoom)		
Jack (Northwest)	Husband	1 hour 34 minutes Video (Zoom)		
Anne (Northeast)	Daughter	1 hour 15 mins Video (Zoom)		
Total		13 hours 02 minutes		6 hours and 58 minutes

Table 9. Information regarding hospital stay.

Table 9		
Carer	Length of Stay of person living with dementia	Reason for Hospitalisation
Carol	Two weeks	Infection
Louise	Multiple admissions	Unclear
Jack	Longer than three weeks	Urinary Tract Infection
Shelly	Multiple admissions	Multiple reasons including infections, falls, crisis in care
Katie	Multiple admissions	COVID 19/other chest infections and related complications
Michael	Multiple admissions	Crisis in care
Harriet	Longer than three weeks	Chest infection
James	Multiple admissions	Frailty, falls
Anne	Multiple admissions	Frailty
Jane	More than three weeks	Fall
Elizabeth	Multiple admissions	Frailty
Abdul	Multiple admissions	COVID 19
Amy	Two weeks	Frailty

Faizal	Multiple admissions	Unclear

4.6.4 The topic of the interviews

The semi-structured interviews included specific questions; the general focus of which participants were informed of via the participant information sheet (Included in Chapter 14). The pre-arranged questions were different for the carer group and the professional group, although both sets of questions focused on wellbeing during the hospital discharge process. I altered the questions to fit the interviewee's role or position, but the content of the questions was largely identical across the interviews. However, the range of responses was large.

Utilising a social constructionist lens meant that carer participants were encouraged to explore the aspects of wellbeing they felt were relevant to themselves and this led to a wide range of topics being discussed within the interviews. The decision to view the discharge process in its extended form led to carers focusing on different aspects of the process, from the day of discharge to the first days in the community post- discharge. While some carers focused on medication or transport, others focused on multi-disciplinary team meetings or documentation. This allowed carers to identify areas they felt were important to them as experts in the discharge process. Professional participant responses displayed more uniformity and less divergence. The impact of COVID 19 penetrated nearly all aspects of the discharge process and arose constantly in discussions due to the study period coinciding with the UK's second lockdown.

The questions aimed to adhere to the tenets of the Appreciative Inquiry model and focused on positive aspects of the experience that could be further developed (Bushe, 2007). Examples of this are: *What support (emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What went well during the discharge process? What support has helped you to maintain your physical and emotional well-being following your relative's hospital discharge?*

These questions aimed to identify positive and generative discussions within the interview (Priest *et al.*, 2013) in accordance with the Appreciative Inquiry approach. Furthermore, the open-ended questions allowed for individual experiences to be highlighted in cohesion with the social constructionist approach.

4.7 The analytic process

I considered several different analytic approaches including grounded theory (Charmaz, 2006) and applied thematic analysis (Guest, MacQueen and Namey, 2011). Grounded theory appealed due to its long-standing establishment within health and social care research and its focus on themes emerging from the field work and raw data (Glaser and Strauss, 1967). However, as previously discussed in this chapter, grounded theories focus on coming to the field with no prior knowledge and its rigid, structured research method did not align with my position as a nurse and researcher in the field, and therefore, my pre-existing knowledge and positionality (Mills, Bonner and Francis, 2006).

The decision to utilise the thematic analysis method occurred after a careful consideration of the benefits and drawbacks of this analytic method, and of others frequently adopted by researchers in qualitative health care research. Ultimately, I valued applied thematic analysis' ability to offer a transparency to the analytic process. This is ultimately important for judging the merit of the findings (Guest, MacQueen and Namey, 2011). I also appreciated the pragmatic approach of the method and its focus on an exploratory, case study format aimed at problem solving and moving beyond descriptive analysis to explanatory considerations (Braun and Clarke, 2013; Braun and Clarke, 2019). I combined thematic analysis with the Appreciative Inquiry method to enable the analysis to focus on the strengths of the discharge process where possible, what was working well, and what participants believed needed to improve. The Appreciative Inquiry process and thematic analysis have been combined successfully in previous research due to the inherent flexibility of the thematic analytic method, and its ability to work in conjunction with an Appreciative Inquiry approach (Watkins, Dewar and Kennedy, 2016).

Applied thematic analysis has a significant history within the context of healthcare research (Elliott and Gillie, 1998; Austin *et al.*, 2000; Goodridge *et al.*, 2005; Tuckett, 2005; Chapman, Hadfield and

Chapman, 2015; Karavadra *et al.*, 2020) and has many positive aspects for the pragmatic healthcare research process and researcher (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2014). Although only recently has it has been fully codified as an analytic method (Flick, 2006). Thematic analysis has been utilised in many important and significant research projects in the field of dementia (Butcher *et al.*, 2001; Leong, Madjar and Fiveash, 2001; Phinney, Chaudhury and O'Connor, 2007; Sun, 2014; Giebel *et al.*, 2020; Fekonja *et al.*, 2021) and hospital focused health practitioner research (Grob, Bläuer and Frei, 2017; Laur *et al.*, 2017). The key aim of thematic analysis is to identify themes which develop into codes and are structured upon 'implicit and explicit ideas in the data' (Guest, MacQueen and Namey, 2011, p.38). The method offers a flexible analytic approach which can incorporate different ontological and epistemological perspectives without being overly prescriptive.

However, the method has not been without its critics (Vaismoradi, Turunen and Bondas, 2013; Braun and Clarke, 2020). Thematic analysis has faced criticism for being ambiguous and for researcher analytic decisions and processes being unclear (Vaismoradi *et al.*, 2016). It is noted that this is a common criticism of qualitative analysis techniques generally that is not limited to applied thematic analysis (Choy, 2014). The justification of the criticism is debated within the theoretical scope of qualitative analysis as it is based on the standards and paradigm of quantitative research which is not applicable to qualitative ontology and methodology.

In response to these critiques, theorists (Guest, MacQueen and Namey, 2011; Braun and Clarke, 2014) have developed flexible but transparent processes which have strengthened applied thematic analysis' ability to support robust analytic findings, and answer the criticisms raised. The development of these measures, which provide a structure and set of procedures to follow within the analysis process, means that whether the analysis process is robust or questionable is now related to the strength of the researcher and the quality of their application of thematic analysis, rather than the method itself.

The applied thematic analysis process aligns well with the context of the health service and is regularly used in this applied context. Healthcare service research is markedly different from other forms of sociological research as it is heavily influenced by the sphere of medical research. Medical research has a positivist outlook and identifies quantitative research as the pinnacle of the hierarchy of research methods. This relationship with medical research has broader implications for healthcare research theoretically and practically, in terms of how researchers develop and think about their research methodology, and how they implement it.

The emphasis on the development of a code book, for example, and the visible development of themes and codes aids the trustworthiness (Auerbach and Silverstein, 2003; Corbin and Strauss, 2008) and credibility (Lincoln and Guba, 1985) of the data, an important consideration in a field heavily aligned with medical research and quantitative methods. The emphasis on member checking and triangulation further supports the more positivistic style of the medical research field. Further to this, the systematic and transparent research process, with a focus on audit trails and clarity, aligns with the rigour of the NHS ethical approval process and the requirements for record keeping.

The inherent movement in the coding from description to analytic interpretation is important for a study hoping to aid decision making around policy, an objective of most research aligned to the field of healthcare. Applied thematic analysis' ability to facilitate both inductive and deductive analysis (Guest, MacQueen and Namey, 2011, p. 37), and to allow structural coding alongside more iterative frameworks, is particularly useful in a context where answers to pragmatic questions are being sought, and rigorous ethical requirements dictate that questions should be known to participants in advance.

In relation to the scope of the research undertaken in this instance, the 'exploratory' (Guest, MacQueen and Namey, 2011, p. 7) nature of the thematic analytic process, alongside the focus on 'solving practical problems' (Guest, MacQueen and Namey, 2011, p. 10) and 'complex social systems' (Guest, MacQueen and Namey, 2011, p. 35), fits well with the objectives of the research project (Guest, MacQueen and Namey, 2011). It also aligns with the Appreciative Inquiry approach which specifically aims to address practical problems and identify solutions. Hospital discharge is a very complex, practical process located inside a multifaceted health and social care institution. Therefore, a process which can pragmatically accommodate this system is ideal. Thematic analysis explicitly allows for processes to be explored (Guest, MacQueen and Namey, 2011, p. 17), and this aligns with the nature of the project to explore the discharge process from different perspectives.

4.7.1 Impact of social constructionist approach on analysis

The social constructionist approach ensured that focus on individual experience, and understanding of the discharge process, was maintained during the analysis process (Blustein, Palladino Schultheiss and Flum, 2004). Instead of focusing on mechanisms or objective external factors, the social constructionist approach enabled a focus on the factors identified specifically by participants through their experiences. During the analysis process, this allowed for an understanding of the multiplicity of concepts, such as person-centred care. Further to this, it enabled an appreciation of the different perspectives of the discharge process held by health and social care professionals and carers.

4.7.2 Applied thematic analysis

In keeping with the tenets and process of thematic analysis, I began by open coding transcripts (Guest, MacQueen and Namey, 2011) using a computer assisted qualitative data analysis package, know as NVivo 12, to identify all emerging themes from the data. I paid close attention to the raw data from the interviews and everything of note was recorded in a ‘node’, within the parlance of NVivo. I coded transcripts as they were available and this allowed me to identify the themes emerging very early in the analysis process (Guest, MacQueen and Namey, 2011). I did not at this point progress to identifying codes as required by the applied thematic analysis method but instead divided segments of the interview transcripts into themes only. There were many diverse themes evident in professional and carer interviews. I chose to analyse carer and volunteer interviews separately to professional interviews. The themes identified within the systematic review and literature review, alerted me that it was probable that the perspectives of professionals and carers would be divergent and therefore, should be analysed separately. This involved reading the transcripts line by line, and creating a new node within NVivo that represented the topic emerging from the data or assigning the section of data to a delineated node within NVivo. This process was completed immediately after transcription was performed, often on the following day. Transcripts of professional interviews were analysed in a separate NVivo file to carer interview transcripts. There was significant duplication of themes at this early stage as aspects of the same theme were analysed individually. Consequently, there was a very high number of initial nodes (104 from professional transcripts and 149 from carer transcripts). NVivo coding examples are included in Chapter 14.

Having conducted the systematic review qualitative synthesis outlined in Chapter 2, I had insight into possible themes that might develop from carer interview data. I avoided explicitly revisiting the findings of the systematic review in detail before completing the initial analysis process. When reading the findings of the systematic review after immersing myself in the coding process, I was pleased to identify that there was correlation in findings. As expected, this excluded the impact of the pandemic. During this time, I composed a descriptive narrative to develop my understanding of the complexities and challenges of the discharge process, wellbeing and how COVID 19 appeared to be impacting on this.

This inductive coding process began to reveal the complexities and challenges of maintaining wellbeing during the discharge process, particularly during the pandemic period. The Appreciative Inquiry approach (Cooperrider and Fry, 2020) allowed me to explicitly focus on areas where the discharge process worked well, and what participants believed either was, or would, support wellbeing. This enabled the analysis to follow the strengths based and generative approach of the Appreciative Inquiry theory (Bushe, 2007). Discussions were held with my supervisors regarding the descriptive narrative text, the content of the data, and how to approach further analysis.

As I identified more and more themes, as I progressed through the transcripts, I began grouping them into dominant, multi themed nodes within NVivo and analysing which themes were emerging as codes in their own right. To achieve this, I looked at each individual node and whether the themes within worked cohesively together, and whether the individual themes were related closely enough to develop a comprehensive code. From this point, I began to develop the beginnings of a code book. Guided by the examples in Guest, MacQueen and Namey (2011), I outlined the content of the emerging codes and wrote a thick description of each code (Geertz, 1973). This process was iterative, and the boundaries of each code were not clear cut in the early phases of code book development.

I utilised the code book to code each subsequent interview, noting whether each theme fit into the code developed or not. The codes within the code book evolved during the subsequent coding process as the input of participants expanded my understanding of the hospital discharge process. The Appreciative Inquiry approach of focusing on the strengths of the process and on proactive ways to improve processes (in this case supporting wellbeing), was central to all analysis and influenced my coding decisions (Cooperrider and Whitney, 2005). Examples of this can be seen in the subthemes such as the Hope subthemes: *Health and social care professionals supporting self-actualisation for people living with dementia and their carers; and the impact of stress on preventing wellbeing, self-actualisation and maintaining hope during the discharge*. The emphasis of the analysis was to build upon that which was identified within the data as supporting wellbeing during the discharge process. Further detail regarding the theoretical concepts underpinning the code development is discussed in the next section of this chapter.

Once I had coded all interviews, I re-read a selection of the interviews with the coding book. This allowed me to assess whether the coding book truly reflected the content of the interviews. I found that the code book did reflect the content of the interviews. There were occasions during the writing up stage where I found repetition of data or not enough content to a particular code to justify its inclusion. When this occurred, I considered whether the content could be conflated with the content of another code.

4.7.3 Further detail of code book development and content of findings and themes

While I was exploring the initial codes generated from the data, I reflected on established academic theory regarding the nature of wellbeing, particularly in relation to people living with dementia and their carers. I returned to Kitwood and Bredin's theoretical writings about personhood for people living with dementia and the importance of wellbeing (Kitwood and Bredin, 1992). It was evident that the key tenets of the theory were identifiable in the data derived from both carers, and health and social care professionals, in relation to the discharge process.

Kitwood and Bredin (1992) identified four 'global sentient states' that could ensure wellbeing for people living with dementia; personal worth, agency, social confidence, and hope (Table 10 outlines this further). Social confidence immediately appeared less applicable to carers and the hospital discharge process in general and did not fit with the early codes emerging from the data. However, the other three areas identified as supporting wellbeing corresponded with the overarching themes emerging from the interview data. Applied thematic analysis (Guest, MacQueen, and Namey, 2011) allows for deductive, structural coding that can enable data to be analysed in concurrence with an established framework or theory. I began re-organising the descriptive themes, from both the carer and professional analyses, according to the tenets of Kitwood and Bredin's (1992) overarching theory of wellbeing. The substance of the themes from the analysis presented here are devised from my own inductive applied thematic analysis (Guest, MacQueen and Namey, 2011), only the overarching themes are derived from the theory of Kitwood and Bredin (1992).

Table 10. Definitions of Kitwood and Bredin's global sentient states of well-being.

Table 10	
Kitwood and Bredin's global sentient states of well-being	Definition. Please see: Kitwood and Bredin, 1992. *Towards a theory of dementia care: personhood and well-being, for further information*
Personal Worth	The deepest level of self- esteem.
Agency	The ability to control personal life in a meaningful way.
Social Confidence	The feeling of being at ease with others.

Hope	A freedom for anxiety if basic needs are met. A confidence that security will remain in a changing atmosphere. The sense that the future will be good.

Table 10 depicts the definitions of Kitwood and Bredin’s global sentient states of wellbeing. I incorporated my own findings from the analysis of the data to expand on the detail of Kitwood and Bredin’s theory of wellbeing (1992) and to explore how this definition can be understood and supported within the context of the discharge process. I created cases and case classifications within NVivo to facilitate the development of a codebook (Guest, MacQueen and Namey, 2011) (An example of this is included in Chapter 14). I also developed a code entitled Dream, in accordance with the Appreciative Inquiry approach (Coperrider and Whitney, 2011). This theme contains the opinions of carers, and health and social care professionals, concerning the areas of the discharge process that are perceived as requiring change. Furthermore, I ensured that the analytic process was focused not on solving problems, but on identifying strengths and potential solutions in accordance with the Appreciative Inquiry approach (Priest *et al.*, 2013). Developing the Dream code allowed me to explicitly utilise the Appreciative Inquiry cycle within the analysis process and draw out from the data the expert opinion of professionals and carers, of the changes required to ensure the maintenance of wellbeing for both carers and people living with dementia. Utilising the Appreciative Inquiry method enabled me to focus both interviews and the analysis process on what works well within the discharge process and what supports wellbeing (Bushe, 2007). This supported me to generate a model of the discharge process focused on supporting wellbeing at a later stage in the analytic process.

I drafted a descriptive, short summary of each of the overarching codes emerging from the data to support the code book in late November/early December 2021. The contents of each code are included in Table 11. Note that codes and themes are synonymous.

Table 11. Code descriptions.

Table 11	
Code	Code description
Personal Worth	This is about valuing and respecting the carer as an individual, alongside the person with dementia, within the hospital discharge process across both the hospital and the community context. Carer identity is conflated with the person with dementia and therefore, their needs must be considered and supported within the discharge process. Person-centred care must include the carer. This has been affected negatively by COVID 19. The importance of which is demonstrated when personal worth is not evident within the discharge process. Must ensure carer is capable of caring and has the training required. Professionals focused on person centred care but often not delivering it. 1. Ensuring inclusive person- centred care (care for the patient and good communication for carer) 2. Being treated as a care partner throughout the process, addressing the power imbalance? 3. COVID 19 impact on valuing the carer of a person living with dementia alongside the individual living with dementia (positive and negative)
Agency	This is about ensuring carers are able to be involved in decision making and that processes, people, and contexts enable that inclusion. Moving away from medicalised ideas regarding risk dominating decision making in relation to people living with dementia. 1. Processes that ensure carer involvement 2. Individuals that support carer empowerment (Professionals often undermine carer empowerment and admit this themselves) 3. Contexts that enable equality (and allow risk taking) 4. COVID 19 and the prevention of agency

Hope	This is a less tangible but vital aspect of wellbeing only achievable when basic needs are met. Respite, financial support and basic support to allow for social activity and hope for the carer and person with dementia. Impact of COVID 19 on this is significant, especially as it is causing uncertainty around community service availability and social contact for carers. Professionals are aware of the impact but not focused on this within the discharge process. Being aware of the impact of being a carer. 1. Moving beyond basic physical needs (Actualisation) 2. COVID 19 and uncertainty (preventing respite, mental health impact and discharge services availability, fear) 3. A supportive environment (finance for carers and carer/patient services)

Table 11 contains a description of the codes generated. Once the codes had been broadly established, I printed a list of the data assigned to each of the four codes and identified what was contained within each. This was a separate process for professional data and carer data. This allowed me to identify the detail of the broader codes in the two interview groups. Once I had identified the internal themes within the broader codes (Table 12), I spent further time looking at the minutiae of these internal themes, and how they would be expressed within the findings. I completed this process across carer and professional data to enable the comparison of these perspectives within each code. This allowed me to identify the differing concerns of the two interview participant groups. I identified the impact of COVID 19 regulations within each code to illuminate the significant impact of the pandemic on wellbeing. Once the internal structure of the codes was established, I wrote small summaries of each code and the internal levels of the themes. Within the four overarching themes of Agency, Personal Worth, Hope and Dream, nine further themes and twenty- six further subthemes were identified and summarized, before the write up of the findings began in earnest.

Table 12. Detail of individual themes.

Table 12	
Professional Themes	**Carer Themes**
Agency	**Agency**
1 Supportive health and social care professionals enabling empowerment	1 Supportive health and social care professionals enabling empowerment
2 Empowering processes	2 Empowering processes
3 Contexts that enable equality and risk taking	3 Contexts that enable equality and risk taking
4 COVID 19 and the prevention of agency	4 COVID 19 and the prevention of agency
Hope	**Hope**
1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)	1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
2 A supportive environment enabling the maintenance of hope	2 A supportive environment enabling the maintenance of hope
3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope	3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope
Personal Worth	**Personal Worth**
1 Ensuring person-centered care	1 Ensuring person-centered care
2 Being treated as a care partner	2 Being treated as a care partner
Dream	**Dream**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in relation to the availability of a social worker	Extensive explanation of the discharge process, including transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options

Additional care package availability in community, including additional support systems	Adequate signposting
Changes beneficial to the person living with dementia and their carer:	Further holistic involvement in the discharge process, including being given choices
Further focus on the wellbeing of carers and people living with dementia	Further respite availability factored into discharge process
Removal of stigma and discrimination from discharge process	Meaningful communication replacing platitudes and inclusion of communication tools
	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

Table 12 reveals the detail of individual themes**.** As stated earlier in this section, while Hope, Personal Worth and Agency are the overarching themes identified by the wellbeing theory proposed by Kitwood and Bredin (1992), the detail of the themes is derived from inductive analysis of the empirical data of this research study and expands this definition into this context.

4.7.4 Conclusion

In this chapter I have outlined the theoretical approach of this research project including the social constructionist ontology and the qualitative method emerging from this methodology. I have also detailed the interview method and some of the challenges of recruitment during the pandemic. Furthermore, I have discussed the Appreciative Inquiry method and how applied thematic analysis as utilised to analyse the data. In the next chapter, I will outline the findings of the analytical process.

Chapter 5. Outline of findings

5.1 Introduction

In previous chapters I have outlined the setting in which this research project took place, and the literature available in relation to the hospital discharge process and the experiences of carers and people living with dementia. This chapter and subsequent chapters detail the qualitative findings of the methods employed. The social constructionist (Berger and Luckmann, 1991) lens was applied to the analysis process alongside the Appreciative Inquiry method (Cooperrider and Whitney, 2005), and Applied Thematic Analysis (Guest, MacQueen and Namey, 2011). Detail of how the codes, code book and resulting overarching themes were developed is included in the previous chapter.

In the following chapters, I will outline the findings of my analysis. I interviewed twenty-five carers and health and social care professionals for this research project. Fourteen carers were interviewed, and thirteen hours and two minutes of data transcribed. Four carers took part in phone interviews and ten carers took part via video interview. The decision to define the hospital discharge process as one extended process meant that it was important to speak to a diverse group of health and social care professionals, including admiral nurses, medical staff, social workers and other allied health and social care professionals. I interviewed eleven health and social care professionals and transcribed six hours and fifty-eight minutes of interview data. All professionals opted to take part in the interview via video interview.

At this point I will re-state the research questions of this research project to demonstrate how the findings of the project addressed these questions: *how can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

Table 13 outlines the individual themes of the four key overarching themes identified through the applied thematic analysis method (Guest, MacQueen and Namey, 2011) that reveal the facets of wellbeing during the discharge process for people living with dementia and their carers. Informal carers and care professionals identified that ensuring Agency, Personal Worth and Hope was crucial to both defining and safeguarding the wellbeing of both carers and people living with dementia during the leaving hospital process.

In response to the secondary aim of developing the definition of wellbeing in this context. The deductive thematic analysis process generated the following definition of wellbeing: *wellbeing during the discharge process is the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond*. The detail of what is meant by 'agency, hope and personal worth' is included in the findings of the analysis presented within the separate chapters.

The concepts of 'agency, hope and personal worth' derive from Kitwood and Bredin (1992) and their theory of wellbeing, but there is little content to these concepts, and they are not reflective of specific contexts. The definition provided here is specific to the discharge process. In this definition the detail is included in the themes and subthemes. Agency is comprised of *empowering processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*.

Within the overarching themes of Hope, Agency and Personal Worth the factors that support the maintenance of wellbeing for this patient and carer dyad are revealed. The themes are delineated in table 13.

Table 13. Themes.

Table 13	
Professional Themes	**Carer Themes**
Agency	**Agency**
1 Supportive health and social care professionals enabling empowerment	1 Supportive health and social care professionals enabling empowerment

2 Empowering processes	2 Empowering processes
3 Contexts that enable equality and risk taking	3 Contexts that enable equality and risk taking
4 COVID 19 and the prevention of agency	4 COVID 19 and the prevention of agency
Hope	**Hope**
1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)	1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
2 A supportive environment enabling the maintenance of hope	2 A supportive environment enabling the maintenance of hope
3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope	3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope
Personal Worth	**Personal Worth**
1 Ensuring person-centered care	1 Ensuring person-centered care
2 Being treated as a care partner	2 Being treated as a care partner
Dream	**Dream**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in relation to the availability of a social worker	Extensive explanation of the discharge process, including transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options
Additional care package availability in community, including additional support systems	Adequate signposting
Changes beneficial to the person living with dementia and their carer:	Further holistic involvement in the discharge process, including being given choices

Further focus on the wellbeing of carers and people living with dementia	Further respite availability factored into discharge process
Removal of stigma and discrimination from discharge process	Meaningful communication replacing platitudes and inclusion of communication tools
	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

It is important to acknowledge that the overarching themes of Hope, Agency and Personal Worth remain subjective terms even when supported by the definition provided by Kitwood and Bredin (1992). However, this subjectivity aligns with the broader social constructionist epistemology of this research project. Agency will not appear identical across different carer experiences. While it is important to clearly define the term, it should also be accepted as having multiple applications and meanings for participants.

Before exploring the content of the themes in individual chapters, three carer narratives will be outlined to highlight the diversity of the care experience and each carers' circumstances. These three carers were specifically chosen to acknowledge the importance of individual experience. Throughout the chapter the differing experiences of carers are highlighted to platform the individuality, and multiplicity of terms such as hope. The individual experiences of Jack, Michael and Katie, are outlined here to contextualise the findings of this chapter within the lived reality of the carer.

5.1.1 Jack

Jack is a carer for his wife who has a diagnosis of dementia.

Jack had a very poor experience of the hospital discharge process. Jack did not feel involved in the process or fully informed or involved in decision making. His wife appeared at home in the middle of the afternoon, in a wheelchair, in a hospital gown, with a blanket, on their doorstep. This annoyed Jack, who was not given warning of the discharge time and could have been out of the house.

Jack receives excellent support from an admiral nurse but found communication with the hospital difficult. Jack has limited community support financially or socially from family and friends. Jack found individuals very helpful but felt that the processes of discharge must be improved.

COVID 19 prevented Jack from visiting his wife on the ward. Jack’s wife’s condition declined significantly during her hospital stay and technology was of limited use. Jack felt that the care received by his wife in hospital did not address her needs as a person living with dementia. Jack found the NHS systems confusing, and the care landscape perplexing in the aftermath of the discharge. He believes that there is limited help available to carers. Jack also discussed how the presence of PPE impacted negatively on his wife’s care and her ability to communicate with health and social care staff.

5.1.2 Michael

Both of Michael’s parents were discharged from hospital to a care home at the same time. Both had a diagnosis of dementia.

Michael had a good experience of the hospital discharge in relation to communication with hospital-based professionals. He experienced both phone calls and a face-to-face discharge meeting, in a pre-COVID era, which were attended by professionals on the ward, and organised by a professional at the hospital (discharge co-ordinator). Michael felt that the discharge went well, and that the availability of hospital transport enabled a smooth transition to the care home.

Michael received excellent support practically and emotionally, from a community-based admiral nurse employed by a charity. He found the process of finding a care home quickly quite difficult, and emotionally very problematic, and has a lot of guilt connected to the process.

The admiral nurse helped somewhat with this feeling, but the guilt is still present. Michael has had no support from social services and has no support in the community. Michael found the caring role very difficult, and it became impossible to manage alongside his career. He believes there should be more support for carers, particularly around financial entitlements, and support services available (if there are any). Michael believes that you are left to get on with the practical and financial measures alone as a carer.

5.1.3 Katie

Katie cares for her dad who has dementia.

Katie had a poor experience of the hospital discharge process overall, with limited communication from the hospital across her dad's multiple discharge experiences. Katie had to repeatedly ring the ward and ask for information and did not feel involved in decision making around discharge despite having power of attorney. Katie was not contacted or communicated with regularly and important information was not passed on. No discharge plan or care plan was apparent at discharge. A kind ward sister compassionately enabled visiting once during the COVID 19 pandemic. Katie experienced many difficulties caused by the absence of ward visiting availability.

Katie was not supplied with relevant medication at discharge and believed that the discharge process was poor prior to COVID 19. Her dad admitted to hospital with COVID 19 following accidently taking GTN (Glyceryl trinitrate) spray in isolation, due to COVID 19 lockdown measures. He was discharged to a care home for emergency respite care and following implementation of a deprivation of liberty order (DOLS), a decision Katie was not involved in, social services quickly decided, after a delay caused by a COVID 19 backlog of work, that Katie's dad should be made a permanent resident.

She believed that her dad was assessed too soon after leaving hospital with COVID 19 having been on a CPAP mask. Katie did not receive advanced notice of the discharge or a discharge letter, and there have been issues with her dad's inhaler following discharge. The care home has refused to administer his inhaler more frequently. This has led to multiple hospital admissions.

Katie has fought to have her dad moved to a more appropriate care home, after her dad was very unhappy in the previous care home. The social worker undermined Katie's input and would only approve a move to another care home after a meeting in a car park, with Katie's dad, and a separate meeting with the care home manager.

The limited visiting available during the pandemic, based on government guidance, has been very distressing to Katie and her dad. Being unable to help her dad or see him has been detrimental to them both.

In the following chapters, l will detail the content of the findings of the analysis regarding the four overarching themes of; Hope, Personal Worth, Agency and Dream. Firstly, the theme of Hope shall be explored, followed by Personal Worth, Agency and Dream

Chapter 6. Hope

6.1 Hope

It was evident from the analysis that the ability to maintain hope during the hospital discharge process was central to maintaining the wellbeing of people living with dementia and their carers.

Within the concept of wellbeing, the sustainability of hope is a difficult concept to succinctly summarise, beyond the definition offered by Kitwood and Bredin (1992), due to its intangibility. However, it emerged within interviews as vital to protecting the wellbeing of carers and people living with dementia.

It was often easier to identify the absence of hope, due to the presence of despair, within carer narratives. However, the Appreciative Inquiry approach enabled a focus on ways of supporting wellbeing within the discharge process (Priest *et al.*, 2013). Therefore, the analysis inverted this finding to identify what prevented despair and what factors enabled hope. The identification of the absence of hope is an important finding as it magnifies the importance of hope within the Appreciative Inquiry analysis.

Being able to maintain hope for people living with dementia and their carers appeared to be supported by two main tenets; the ability of the discharge process to consider more than purely physical needs and logistics, and the availability of a supportive environment, both socially and financially, that allowed self-actualisation for both the person living with dementia and their carer.

This section of the analysis draws on Maslow's (Maslow and Lewis, 1987) theory of the hierarchy of needs and the concept of self-actualisation. Maslow suggests that human beings have a hierarchy of needs starting with basic physiological needs and moving through the levels of safety, love and belonging, and esteem, to the highest level of self-actualisation. Maslow defines this as being the most one can be when all other lower needs are fulfilled.

A significant portion of the analysis of the data from both professionals and carers, reflected how the integral uncertainty caused by the pandemic had a negative impact on the ability of people living with dementia and their carers to maintain hope, and prevented movement through Maslow's hierarchy of needs. Fear, isolation in the hospital context, and limited community service availability, made the maintenance of hope difficult during the discharge process. Uncertainty around discharge options complicated decision making, and limited social contact led to patients deteriorating in hospital. Carers revealed the significant stress that uncertainty caused by the pandemic created.

Table 14 reveals the main subthemes that emerged in relation to the importance of hope for maintaining the wellbeing of carers and people living with dementia. The Impact of the Appreciative Inquiry approach in identifying potential strengths, and ways to improve the process is evident within the subthemes. The social constructionist emphasis on valuing individual insight is also evident.

Table 14. Hope. Themes and subthemes.

Table 14
Theme 1 The importance of supporting self- actualisation for maintaining hope (Moving beyond physical requirements)
Subtheme 1.1 Health and Social Care Professionals supporting self-actualisation for people living with dementia and their carers
Subtheme 1.2 The impact of stress on preventing wellbeing, self-actualisation and maintaining hope during the discharge process
Subtheme 1.3 Carer insights into how to maintain hope and move towards the actualisation of wellbeing for both carers and people living with dementia
Theme 2 A supportive environment enabling the maintenance of hope
Subtheme 2.1 Ensuring adequate finances and services for carers
Theme 3 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope
Subtheme 3.1 Pandemic related fear

Subtheme 2 Isolation in the hospital context caused by pandemic regulations
Subtheme 3 Limited-service Provision

Table 14 outlines the themes and subthemes of this concept. The first theme to be considered is the importance of being able to move towards self-actualisation, and away from purely physical considerations during the discharge process. This theme details some of the ways in which the ability to maintain hope can be prevented during the discharge process. This is important to note even in an Appreciative Inquiry project as theorists such as Reed (2007) identify that all findings must be presented to increase validity and transparency within the research process. I will begin by considering how health and social care professionals acknowledged that being aware of the necessity to support needs, beyond physical requirements, can help to support a movement towards self-actualisation for people living with dementia and their carers. Due to carers having greater insight into the importance of maintaining hope, their views are centralised within this chapter. The analysis of professional data and carer data is presented together in order to compare and contrast findings.

6.2 The importance of self- actualisation for maintaining hope (Moving beyond physical requirements)

6.2.1 Health and social care professionals supporting self-actualisation for people living with dementia and their carers

The analysis showed that the intangible need to maintain hope, and the indeterminate but vital factors that allow for self-actualisation, were rarely mentioned during interviews by most of the professional participants in comparison to carer data. However, some professionals displayed a significant understanding of the importance of moving beyond considering only the physical requirements of the discharge process and reinforced a movement towards helping to support self- actualisation for people living with dementia and their carers.

> *Occupational Therapist: I think you're looking at the here and now. How the client is feeling in the here and now. Make sure it's as positive an experience as possible. Valuing their thoughts or valuing their feelings, validating their thoughts and feelings as well. Even if they don't necessarily make a lot of sense, the feelings still need to be validated and taken into consideration. But I think then it's also looking for the future, its giving people hope, it's giving people a sense that there is a future to be enjoyed and yeah, and life is good'.*

Specialist dementia nurses displayed a sincere and thoughtful understanding of the emotional impact of the discharge process for the person living with dementia, particularly if the discharge destination is a care facility.

> *Specialist Dementia Nurse 3: Sad and angry, there'll be lots of emotions about it. Somebody decided you're not capable of going home. That it is better for you go somewhere else, you don't get a choice in where you go, because your family choose that for you. And you just end up sort of being taken to a room, with a few things that somebody else has chosen for you and that's it for the rest of your life and actually your property's probably being sold to fund that.*

The importance of explicitly acknowledging the need to maintain a sense of hope for the future to ensure wellbeing was discussed by some professionals within the interview context. However, the acknowledgement of the thoughts, feelings, emotions, and non-physical aspects of care for the person living with dementia and their carer, was not a common occurrence within the professional data.

Health and social care professionals that did have significant insight into the emotional difficulties of the discharge process, also had an awareness of the challenge's integral in the process for both groups. Anger experienced by people living with dementia over the loss of control regarding where they can live, and their lack of closure if they cannot return to their own home, was identified as preventing the maintenance of hope.

This highlighted the significant impact that discharge destination plays in relation to being able to sustain hope during the process. The Appreciative Inquiry approach allowed for the identification of the importance of ensuring an appropriate discharge destination environment, which is welcoming from both an emotional and comfort standpoint. One participant identified that making sure that the discharge destination was appropriately prepared for the person living with dementia was central to this. The requirement for awareness of the needs, beyond care packages and physical care assistance, that support individual wellbeing and the maintenance of hope was acknowledged. Specialist nurses identified the importance of ensuring that people with dementia feel supported and cared for. In relation to carers, the importance of being able to express their emotional condition, and find support beyond practical assistance, was evident for maintaining hope.

> *Occupational Therapist: We need to get this equipment in before, we don't want the client coming home before we've done all of this because it will be unsafe, or it will be in too much of a muddle that it wouldn't be good for the client. We want it so that, so once their home, they can just relax and all the changes have been made and the environment is as it should be, rather than having to make more changes once they get back home.*
>
> *Specialist dementia nurse 3: They are mentally in the best place possible, so, although they're in a hospital ward or hospital bed, which is not nice, that they feel supported and cared for, and that people are acting in their best interest and doing the best to get them moved on, as quickly as possible.*

Interestingly, the limited discussion amongst professional participants in relation to the maintenance of hope was commented upon by one participant, who felt that this aspect of wellbeing is not directly addressed by health and social care professionals in practice. The participant believed that this is due to the demands of their professional roles, which call for focus on other more tangible parts of the discharge process. It was identified that this results in less perceptible aspects of wellbeing, which are not related to physical needs, being overlooked.

> *Social Worker: I think that, for wellbeing, I think it's just, it's, it's looking at that person holistically, isn't it? And making sure that every aspect of their needs are met and if, you know, if somebody is unhappy and they're expressing, you know, that they feel that a need isn't being met and we need to respond to that instead of, 'cause, I think sometimes professionals can be a bit blinkered because of the pressures of work and the through put.*

That many of the professionals did not focus on the emotive aspects of the process, but instead on objective realities and practical discharge processes, stands in contrast to the much more emotionally focused carer perspective. In the next section, I will consider how the presence of stress prevented the maintenance of hope and self-actualisation for the carer during the hospital discharge process.

6.2.2 The impact of stress on preventing wellbeing, self-actualisation and the maintenance of hope during the discharge process.

The significantly stressful nature of the discharge process was discussed by nearly all the carer participants. Some carers experienced a sense of respite while awaiting their relative's hospital discharge due to being relieved of their daily caring role. However, many carers found it exceptionally stressful attempting to be involved planning and organising a successful discharge process.

> *Abdul: I think the experience is quite emotional and relief, so you kind of, I'm a carer you see for my mom and when she's in hospital, it gives me a sense of break, because I think at least she's there with the right staff and support. Obviously, you still have the anxiety and you think maybe she's not happy with the hospital food and I will take some food for her, I need to visit, she might get lonely. She might need company, but at the same time you kind of feel like it's so nice just not having to have to think about somebody all day.*

Carers referenced the impact that being a carer had on their lives and some of the negative consequences of the role outside of the discharge process. Carers discussed the day-to-day stress and uncertainty linked to being a carer, the loss of identity and fundamental life changes the role could cause, as well as the wider impact on the family dynamic and poverty from the loss of employment. All of these elements could make maintaining hope difficult for the carer during the hospital discharge process.

> *Katie: It just [adequate support] doesn't exist, and I found that out and I was working full time up until last year and it was because of dad, I had to give up my job because I literally couldn't*

> *stand the stress of it anymore, and I didn't want to go on the sick, and I had worked 38 years.*

These personal factors caused by becoming a carer played a significant role in the hospital discharge process as they represent the context in which decisions are made. Within the discharge procedure, the organisational process could be very demanding for the carer. Carers discussed how difficult and exhausting the endless phone calls to enable discharge decisions and arrangements could be, and the challenge this presented to maintaining their wellbeing and a sense of hope for the future.

> *Jane: There's probably stuff went on in the background that I've no idea about, so maybe I'm running them down a bit. But yeah, we did everything* ***. It felt like we did everything*** *.*

The pressure linked to fluctuations around changing plans, particularly on the day of discharge itself, were difficult for carers to adjust to. The sometimes-devastating emotional impact of the process, and its effect on wellbeing and the maintenance of hope were discussed. Jack in particular mentioned attempts not to cry on the day of discharge itself. Interactions with health and social care professionals could make maintaining wellbeing challenging, with carers describing being subjected to projected guilt linked to decision making around the discharge.

> *Jack: Yeah, so, so, my wife was in a terrible state. I nearly burst into tears, you know, I was quite shocked when I saw her. It was like, she's like I envisaged her to be in about four- or five-years' time.*

Maintaining a sense of hope during a care home destination discharge for the person with dementia was particularly challenging. Carers described struggling to cope with the shock and guilt of the decision, even when it was the right decision for the carer and person living with dementia.

> *Michael: I think, you know, you have these feelings of guilt, when you, when they go into a home, And I've been through that as well and it's, it's,* ***just not a pleasant experience*** *.*

The financial complications that accompany a care home placement made this process particularly challenging. James discussed the potential financial impact of the cost of funding a care home placement, the potential to lose his home in the future and the impact that had in relation to his ability to maintain a sense of hope and wellbeing. Another source of tension came from carers having to explain to their relative that they required a care placement, and the inevitable conflict if the person with dementia wanted to return home. Jane discussed her fears that her grandfather would fight a care home placement, even though he lacked the capacity to make independent decisions. Further to this, carers worried about the emotional impact of the transfer to a care home for their relative. The image of his mother on her own, in an empty room, in an unknown care home, was very distressing to James. Harriet summed up the symbolic difficulty of the decision to sell a property to fund a placement and the challenge such an action presented to the maintenance of hope.

> *Harriet: the thought of his bungalow gone, you know. That, it was all going to be really difficult. But it took a good while to find a care home place.*

However, whilst the stressful nature of the discharge process could make maintaining hope difficult, carers had excellent insights into ways to maintain hope during the discharge process. In accordance with the Appreciative Inquiry focus on vital and positive areas to build upon within a process (Scerri, Innes and Scerri, 2019), I will outline these insights in the next section.

6.2.3 Carer insights into how to maintain hope and move towards maintaining wellbeing for both carers and people living with dementia during the discharge process.

Carers had significant insight into ways to maintain hope and enable movement towards the actualisation of wellbeing during the discharge process. For people living with dementia, carers felt that taking care of little things to ensure their comfort was important. Enabling the person with dementia to choose to continue activities they enjoyed post-discharge, even if there was some risk attached, was felt to be vital to maintaining a sense of hope during the discharge process. Further to this, valuing and not objectifying the person with dementia was identified as integral.

> *Harriet: It was something I just had to make a trade off in my head about that, do I stop him drinking alcohol completely? I just decided to bear, whatever risks were involved with his drinking because he was getting so much enjoyment and social interaction out of it.*

Carers mentioned that discharge planning should aim to empower people living with dementia in a way that recognised their mental health and encouraged their abilities. One example of this was recognising the value of organising social activities to commence in the community, such as attending a day centre or music group. Carers also described ways in which they felt supporting the personhood of the individual living with dementia was vital to maintaining a sense of hope during the discharge process. Story telling such as this revealed generative ways that the discharge process could be improved, as has previously been identified in the work of Havens, Wood and Leeman (2006).

> *Louise: To me, the power of music is, is, is, the ultimate thing with, with, anybody, and especially with people with dementia. They come in, so a lot of the time with their shoulders down and they sort of amble to the table, and they sit down and then they go out and they're tall, or they're walking taller, and they've got a smile on their face and they absolutely love it. And they get a coffee and a biscuit while they're there and yeah, it's generally good fun yeah*
>
> .

For carers themselves, knowing that respite would be available as part of the discharge package, and that this would allow them time to pursue social activities and hobbies was vital to maintaining hope. A key element emerging from the analysis for maintaining a sense of hope was ensuring that the discharge process factored in carers having an element of freedom within their lives. This sense of freedom was often depicted in narratives as fleeting but vital.

> *Elizabeth: Early on, that when the carers came for their first visit of the day, which was the longest one to wash and dress him. I*

> *mean, I did my husband's breakfast first thing and then the carers would arrive to wash and dress him so that was in theory, that was an hour's visit. And so, I would go out for a walk every day and get myself a coffee while they were doing that. So, I just knew, whatever else happened the rest of the day at least, you know, I'd been out.*

Further to this, carers and health and social care professionals identified a supportive environment as essential to maintaining a sense of hope throughout the process. This shall be explored further in the next section.

6.3 A supportive environment enabling the maintenance of hope: Finances and services for carers.

Health and social care professional's recognised that the availability of a supportive financial and service environment during the discharge process was necessary for maintaining hope for carers and people living with dementia. Adequate and predictable finances, and the availability of services in the community was identified as fundamental by both professionals and carers to the maintenance of hope. Similarly, carers had a detailed insight into the impact of an inadequate environment and the harrowing impact of this on their wellbeing.

> *Shelly: I mean, I was probably about 8 stone when this all happened and I'm six stone now. I literally forgot to eat. I never went to the hairdressers, never went anywhere because I couldn't afford it, because I had no money.*

The value of service provision was understood and illustrated by both professionals and carers, and the impact of unavailable services during the pandemic was lamented by professionals.

> *Specialist dementia nurse 3: And I think that especially as lockdown's been going on, a lot of families have been under pressure 'cause they have been not provided that support, as multiple teams are being closed and voluntary sectors haven't been able to go in.*

The analysis revealed that carers almost universally grieved the limited support available in the community, and the limited signposting offered by health and social care professionals. This led to carers feeling extremely challenged due to the absence of required services. Many carers expressed their puzzlement that basic signposting did not occur. Multiple carers identified that potential support options in the community were not signposted during the opportunity of the discharge process, nor was adequate support offered from the hospital. Carers also discussed how attempts to seek support were rebuffed by professionals in the community, who instead suggested it was the hospital's responsibility to address carer concerns. This left carers unsure where to turn for support. In contrast, health and social care professional participants generally did not address the limitations of the support or services available to carers, nor their impact on carer life and wellbeing, with any frequency or in any depth.

> *Interviewer: And did anybody kind of offer you any support?*
>
> *Jane: [Starts laughing] No! Is that a joke? [laughing] No is the short answer? Uhm, I don't know whether I can give you a longer answer. Certainly not me and not mom either.*
>
> *……from the hospital level and from when all this happened and a discharge point of view, absolutely nothing at all.*

The Appreciative Inquiry approach allows for a focus upon services and professionals who represent strengths within the current process. Admiral nurses were highly valued for the support they offered during the discharge process. Admiral nurses were identified as a particular asset within the process due to their supportive nature and role. Outside of admiral nurses and dementia charities, carers were reliant on Google to answer their queries, much to their surprise and dissatisfaction. Even charity support was identified as being of limited utility at times. Social services were accused of offering little to no provision and of making accessing any type of support difficult. This was due to the bureaucracy of the social care system and financial cutbacks leading to limited funding availability.

> *Michael: Well, you know, without the admiral nurse to be honest, I wouldn't have, he was advising all the way through. To be frank, there was nothing from social services really.*

Instead of offering help and guidance, social services were reluctant to share details regarding available services. This led to distress for carers and people living with dementia. The omission of advice or provision of respite services was identified as a particular problem for carers, as it prevented advance care planning. One carer identified that due to the lack of support available in the community, they had to pay for a private carer and were denied help and support by social services. However, some carers did receive support from the social care sector in relation to respite and wellbeing. This financial support was greatly appreciated by carers. In accordance with the Appreciative Inquiry approach, this highlights the importance and strength of having a supportive financial and service context, in enabling people living with dementia, and their carers, to maintain a sense of hope.

*Shelly: But what social services should have told me was she could have got a place in a bungalow for dementia. Beside the *****, totally designed for dementia care, and social services, never told me that, they never offered any respite or any funding.*

Shelly: The only thing I got was, 'oh there's an emergency bed'. I didn't want an emergency bed, I wanted to be able to plan. When I wanted mum looked after, where I wanted her to go because I wanted to look at how the budget, so I could be in charge of what I was paying for.

The biggest concern of carers, identified within the analysis, was the absence of financial support available, and the absence of guidance to help carers manage their finances. The complicated and convoluted nature of the assessments required to access financial support were identified as a significant barrier to accessing financial aid for carers. They were also depicted as difficult to complete during the discharge process. The fear and stress caused by the financial implications of care home costs on property and income were discussed. The opaque nature of the charges and costs of care packages were also criticised.

Elizabeth: The only real issue I ever had, which is now resolved was….. As you know, social care is means tested, our local authority didn't have, they didn't seem to have the operating infrastructure in place to actually produce appropriate invoices. I mean, I wasn't saying I don't think we shouldn't be paying, we should...I, with power of attorney, I didn't feel I should be paying

> *for something, unless I had a piece of paper telling me what it was for.*

The lack of clarity around financial matters, and limited services, was acknowledged as being exacerbated by the pandemic. This shall be further discussed in the following section. It is important to detail negative experiences within the Appreciative Inquiry approach as it can highlight areas that be developed and avoids the criticism that Appreciative Inquiry ignores negative experiences (Trajkovski, Schmied, Vickers and Jackson, 2013).

6.4 Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope.

A significant portion of the data reflected how the integral uncertainty caused by the pandemic impacted negatively on the ability of people with dementia, and their carers, to maintain a sense of hope. Fear, isolation in the community, and limited community services made maintaining a sense of hope difficult for carers, and people living with dementia, during the hospital discharge process. Uncertainty around discharge options, complicated decision making, and limited social contact, led to patients deteriorating in hospital, and carers experiencing very high levels of stress.

Professionals had a significant insight into how the pandemic caused uncertainty within the discharge process. Carers displayed a profound individual understanding of the pandemic's ability to prevent hope, but tended to generalise how the pandemic was preventing hope generally, rather than in relation to the discharge process specifically. The pandemic and its associated regulations, impacted on every aspect of the carer and person living with dementia's daily existence. This made it difficult for carers to disassociate the impact on the discharge process from the generalised impact.

Due to professional participants being able to articulate a clearer vision of the impact of the COVID 19 pandemic on the ability of people living with dementia and their carers to maintain hope within the hospital discharge process, the professional data shaped the final structure of the findings presented. Carer data aligned with the professional perspective and is highlighted throughout. This finding is in opposition to many of the other findings in this thesis in relation to other areas of wellbeing.

The analysis of the data revealed three key elements causing uncertainty within the discharge process and preventing carers and people living with dementia from maintaining a sense of hope and wellbeing. These were: fear of the virus; the impact of isolation in the hospital context caused by COVID 19 regulations; and limited-service provision in the community.

6.4.1 Pandemic related fear.

Fear of the pandemic contributed significantly to the presence of uncertainty within the discharge process. The analysis revealed that professionals believed that fear of catching COVID 19 prevented carers making decisions that were in the best interests of the person living with dementia. An example of this was carers opting not to visit their relative in hospital to help prepare for the discharge, when visiting was available to them, to the ultimate detriment of the person living with dementia and the carer themselves.

> *Specialist dementia nurse 2: But what's happened, of course, is that people are fearful, and so they choose not to come in because of the high risk, and so they are made very aware of the risks. And then I think, they think, wait a minute. If I'm old and vulnerable as well, coming in could put me at risk, so they definitely saw a huge downturn in the number of visitors. And so, the impact that has is, and I see it a lot, where the therapy staff are struggling with somebody to get them home, with following tasks, you know, being involved in adls [activities of daily living] things, moving and handling or whatever it is and always say, actually with the wife or the husband or the person that person feels most comfortable with, is here, that has an impact.*

It was manifest from the analysis that the media's portrayal of the pandemic was having a detrimental impact on carer decision making and creating a reluctance to visit acute settings. It was evident that this was impacting on the ability of professionals to build relationships with carers and plan the discharge process appropriately. This fear was articulated by carers themselves, including a reluctance by people living with dementia to enter the hospital. Carers were able to coherently discuss their fear, and even terror of COVID 19 in relation to themselves, but primarily discussed their concerns for the potential impact on the person living with dementia.

> *Abdul: At the last minute, they wanted to admit her to hospital, and she was frightened of all the stories about people going in and not coming out. And she refused to go in, the patients is like, I'm not going in because there's no chance they're going to send me back home alive. That was kind of a myth that the media has portrayed.*

Professionals identified that carers were reluctant to have domiciliary care workers enter their relatives' homes and were keen for hospitals to quickly discharge people living with dementia. This led to fears around catching COVID 19 being prioritised above the need to make the best discharge decisions possible for the person living with dementia.

> *Nurse 1: One patient we have now, we think she's going to need care at home but the family are dead against it until she has the COVID vaccine. And she's 101. But the son is very clear, we don't want any external carers until she's had the vaccine.*

Similarly, professionals noticed a reluctance on the part of carers to accept the person with dementia back home following hospital admission. Carers discussed how this reluctance to organise a home discharge stemmed from fears of catching COVID 19 and fears that their relative had deteriorated during the hospital admission. There was also anxiety expressed regarding being 'locked in the house' for long periods of time during lockdowns. Similar fears led to carers being reluctant to consider care homes as discharge destinations, due to the inability to visit individuals within care homes, and the incidence of COVID 19 within the care home setting. This reluctance led to conflict between professionals aiming to support the needs of people living with dementia and carers reluctant to expose their relatives to the perceived risks of care home admission.

> *Specialist Dementia Nurse 4: The isolation from COVID for patient's carers has meant there's a real reluctance for people to have people back from hospital. Whereas before people would have*

> *had people back, I think the thought of being locked in your house with somebody, maybe for another three or six months, is too much for some people to comprehend.*

The analysis showed that care home admission was the source of much strife for carers due to inherent uncertainty within the process. Changing rules around PCR (Polymerase chain reaction) tests and isolation periods, made an onerous and uncertain situation more difficult. Carers were separated from their relative by a scarcity of availability to visit both in the acute setting, and when their relative was discharged, and consequently did not know whether adequate discharge plans were in place. Further to this, carers felt acute distress from the extended separation periods. They often reported feeling that they were struggling with uncertainty in relation to what was allowed, including being physically present on wards and being involved in discharge meetings. Carers expressed a sense of powerlessness caused by fear of COVID 19, and also by the changing regulations which made certainty and hope difficult to achieve during the discharge process. This was particularly true for people living with dementia who were exposed to multiple and frequent isolation requirements on leaving the hospital setting, even with a negative PCR result. It was evident from the analysis that maintaining hope and wellbeing was an exasperating challenge for carers during the pandemic, particularly in relation to isolation requirements.

> *Katie: It was, it just kind of felt like dad went into hospital with COVID, he was treated for the COVID, he wasn't treated for the Alzheimer's or supported with the Alzheimer's. I couldn't get in [to the hospital], the dementia specialist staff couldn't get in and he was discharged without any sort of plan in place. And it's always to do with, it's the dementia side of it just gets completely forgotten about. They don't treat or support any of that for their wellbeing. They should try and keep them as, as, rehabilitated, as they were prior to their admission.*

6.4.2 Isolation in the hospital context caused by pandemic regulations.

It was evident from the analysis that the changing regulations of the pandemic, the potential for further lockdowns, limited social opportunities, enduring isolation, and ambiguity around what was permissible in the acute setting, created continuing uncertainty within the discharge process. In the acute setting, professionals identified that there was significant doubt around how to care for people living with dementia on the hospital wards. Accepted good practice regarding care for people living with dementia in the hospital setting was at times unavailable, due to uncertainty around COVID 19 regulations and social distancing. Group activities to promote socialisation were prevented. Professionals identified that people living with dementia lost tactile care vital to their wellbeing due to pandemic regulations and isolation guidelines. Professionals identified that technology could not replace the needs of people living with dementia in ways that were possible for individuals living without dementia. Technology replacing face- to- face contact was identified as particularly detrimental with a specific negative impact on privacy and dignity.

> *Specialist Dementia Nurse 3: I mean there's the loss of touch. You know, people want to be close to their relatives, they want to see them in person, they, you know, they want to be able to hold hands and things like that. You know, all of those, they can't be translated into a virtual contact, can they? Or if you want to give someone a hug, you can. Or make somebody a cup of tea and hold their hand. None of those things really can happen if you're on an iPad, can they.*

Isolation and limited-service provision in the acute setting was also reflected in the community. This will be outlined in the next section of this analysis.

6.4.3 Limited-service provision.

It was evident from carer data that the isolation experienced in the community impacted on their wellbeing, and the wellbeing of the person living with dementia, particularly in relation to the detrimental impact of lockdown upon cognitive ability. This decline in wellbeing was linked to the absence of service availability and uncertainty around what would be available both immediately, and in the long-term following the discharge. This uncertainty impacted upon decision making during the discharge process because what would be available to carers and people living with dementia, long or short term, was unclear. This made deciding key elements of the discharge plan difficult for carers and professionals, as both care package provision and day centre availability was steeped in ambiguity.

> *Consultant: So, I think that's you know. Obviously, people do clinically deteriorate as well, so that's an uncertainty. But the biggest uncertainty I have at the moment, and the biggest I think frustration in my practice I have at the moment is the availability of community care and that has hugely, hugely deteriorated since COVID.*

Uncertainties around employment caused by the pandemic, contributed to difficult discharge decision making. Carers were uncertain regarding the long-term availability of mechanisms such as furlough. In response to this, professionals tried to counteract the limited-service provision in the community by further signposting, and offering more informational support before the person living with dementia left the hospital setting. Sometimes this was delivered over the telephone to the carer. Another issue for professionals and carers included the uncertainty surrounding funding for discharge, with changing goal posts around funding availability causing ongoing problems.

> *Social Worker 01: Well, it's, it's just, just been extended, because we did think it was only gonna be till 31st of March, so again, we had this scramble to do, to move the reviews and get everybody out of that funding by the 31st of March. And then we're told actually, it's going to be extended, but only for hospital discharge now and not for hospital avoidances.*

Carers and professionals were united in their view that limited community services had led to significant deterioration in people living with dementia, with a corresponding impact on their wellbeing. The lack of respite and services available to carers to pursue relaxation and hobbies during lockdown also caused significant deterioration in carer mental health. The data from both professional participants and carers demonstrated that the ongoing uncertainty around community provision and support, lockdowns and isolation, impacted on the ability of carers and people living with dementia to maintain a sense of hope and plan effectively for the hospital discharge.

> *Specialist dementia nurse 2: And even things like the day centre shutting, those are things that kept people well. Churches shutting, the anxiety around, going to regular services, those things that could have made a mark in your week...... So, then people came in more confused.*

This section has demonstrated the importance of the maintenance of hope in ensuring the wellbeing of people living with dementia and their carer during the hospital discharge process. These findings develop the content of the concept of hope and its value to wellbeing, as outlined by Kitwood (1997), within the confines of the discharge process. During the discharge process, it was identified that considerations beyond just physical requirements were essential for the maintenance of hope for people living with dementia and their carers. The impact of stress on the ability to maintain hope, and the value of health and social care professionals who support the movement towards self-actualisation, were evident within the analysis.

The Appreciative Inquiry method highlighted carer insights into how to maintain hope during the discharge process. Carers identified the value of holistic care and adequate respite availability through their narratives. Further developing this, the importance of a supportive environment financially, and adequate service accessibility, was revealed through the analysis of carer data. One of the strengths of the Appreciative Inquiry method is its ability to focus on context specific strengths and weaknesses (Reed, 2007). I identified the way fear, isolation in the hospital context and limited-service provision, caused uncertainty during the pandemic and undermined the ability of people living with dementia and their carers to maintain hope during this period. This demonstrates the value of the Appreciative Inquiry method for identifying areas that require development within a process and what might be useful to Dream about further.

In the next section, I will move on to elaborate on the second theme identified within the analysis: the importance of ensuring the personal worth of people living with dementia and their carers. Ensuring the personal worth of the person living with dementia and their carer is central to ensuring their wellbeing during the discharge process. This theme reflects the value of person-centred care, communication, safeguarding and the importance of being treated as a true care partner, throughout the discharge process for supporting wellbeing.

Chapter 7. Personal Worth

7.1 Personal Worth

It was evident that ensuring the personal worth of the person living with dementia and their carers was vital to ensuring their wellbeing during the discharge process. The analysis yielded two main themes in relation to personal worth: ensuring person centred care; and that carers and people living with dementia are treated as care partners during the discharge process. The influence of the Appreciative Inquiry approach on the analysis process can be identified in the focus on how to ensure holistic, person-centred care. Table 15 outlines the themes and subthemes of personal worth.

Table 15. Personal Worth. Themes and subthemes.

Table 15
Theme 1 Ensuring person- centred care to support personal worth
Subtheme 1.1 Understandings of person- centred care
Subtheme 1.2 Communication
Subtheme 1.3 Safeguarding as a pillar of holistic care
Subtheme 1.4 Discrimination
Theme 2 Being treated as a care partner

7.2 Ensuring person centred care to support personal worth

This section explores how the analysis revealed that ensuring holistic and person-centred care supported the personal worth of both carers and people living with dementia during the hospital discharge. Person centred care was identified by carers and professionals as including **understandings of person-centred care; positive and adequate communication; adequate safeguarding; and an environment free from discrimination.** I will first discuss the nature of person-centred care as defined and understood by health and social care professionals and carers. As in previous chapters, the analysis of health and social care professional and carer data is presented side by side to highlight where perspectives align or differ.

7.2.1 Understandings of person- centred care

The analysis identified that both professionals and carers felt that person centred care was integral to ensuring the personal worth of both the carer, and the person living with dementia, during the entirety of the hospital discharge process. However, the understood definitions of person-centred care were not identical for these two participant groups. For professionals, person centred care primarily reflected objective concerns, such as centring the person living with dementia through practical actions and decision making, while validating their wishes in conjunction with the needs of the carer.

> *Occupational Therapist: Okay, and what it's very much the client being at the at the epicentre of all discussions and including them as much as possible so that they actually feel that they've got that element of control and that they're still important so, centralizing all discussions.*

From the perspective of carers, person centred care involved feeling emotionally supported with consideration being shown to the individual requirements of the person living with dementia. Kindness, compassion, and taking the time to support both the carer, and the person with dementia was valued. Carers highlighted small, caring actions as epitomising person- centred care. These opposing perspectives demonstrate the differing approaches to this aspect of wellbeing and reveal how the concept of personal worth and person-centred care, is a dynamic entity with multiple meanings. In alignment with the Appreciative Inquiry method, carers were able to identify and narrate specific instances when they felt that they experienced person centred care. This is demonstrated by the extract from Harriet's transcript.

> *Harriet: And it was, you know, they did have the clinical aspect covered. But they also had this very nice kindness and compassion, you know that to me, I don't often meet in the hospital scenario. Because it is more clinical. So, it was the emotional support for me, the emotional support for him, and you know it was all very, very good, excellent.*

Taking time to support carers was identified as beneficial by different health and social care professionals. Professionals were cognisant of the need for carers to receive and understand how to access appropriate support. However, professional concepts of support leaned towards assistance around the processes and conditions of care, rather than the carer focus on emotional support. Professionals identified support as aligning with informational and practical assistance, particularly in relation to understanding dementia as a medical condition and its prognosis. While this is an integral part of the support required by carers, it diverged from the carer focus on intangible, emotional support. Carers identified that true person-centred care moved towards a holistic view of the patient, and a careful consideration of the impact of their dementia diagnosis on their requirements during the discharge process.

> *Specialist dementia nurse 3: Things do change, that we've got access to the support services, so that they're not feeling overwhelmed by kind of the change in care need, or the change in this support that they are having to provide from the care point of view. And can access that help or support.*

> *Katie: The proactive bit is missing.*
>
> *All of these places, and it just makes you worry, to what extent wellbeing is taken into consideration, especially with people with Alzheimer's or dementia. It seems to be that bit just doesn't exist, whereas, that is actually part of the whole thing, as well.*

It was evident from the analysis that the carer definition of person-centred care was vital to ensuring the personal worth of people living with dementia and their carers. Conversely, an absence of person- centred care was experienced by carers as a discharge lacking in basic humanity, with a corresponding detrimental impact on personal worth. Losing valued personal items or having personal items treated with a lack of care was interpreted as a reflection of the worth assigned to the person living with dementia and their carer. Professionals and carers agreed that ensuring person-centred care fundamentally relied on positive and inclusive communication between professionals, carers and the person living with dementia. Carers argued that particularly poor communication resulted in a discharge process that lacked humanity and could be very upsetting to carers with a low tolerance for brisk and functional communication.

> *Jane: I recognize that they're probably stressed and so are maybe not wording things in certain ways that are supportive or that they're not giving, maybe, accidentally not giving, us the opportunity to input into something. Because you know, because they've just not got time and, you know, being bounced around different people at social services, I get it, that it's probably an artifact of a stretched service, but it's still. I felt as if the humanity aspect of it was kind of removed a bit too much, you know, ...*
>
> *I just think that that, like I said, that like, there was just no humanity in it or very little humanity in it.*

The importance of adequate communication in ensuring person centred care shall be considered more explicitly in the next section.

7.2.2 Communication

Communication was often characterised by health and social care professionals as a one-way communication of information, from the health and social care team to the carer and patient. Although this was often framed as a discussion, language choices by professional participants revealed that the professional was viewed as the active communicator within the relationship, and the carer or patient as the passive partner. Discharge targets and goals were largely dictated by the professional member of the communication relationship. Further to this, professionals did not provide clarity in their responses regarding what could be considered 'good communication,' instead leaving the parameters of what constituted positive communication undeveloped.

> *Consultant: So, often on my ward rounds I would say to my patients and their relatives, ok so, like, these are the goals that you need to meet before going home. So, sometimes it's medical stuff, so say, you know, for somebody who is perfectly well and is mobilizing around the ward but is on oxygen, I'll say: 24 hours after you come off your oxygen, you can go home.*
>
> *And, so, the patients know what the goals are, they are trying to meet and what things they need to tick before they can come home. And the carers know that as well.*

Positive communication that enabled person-centred care was highly welcomed by carers. The Appreciative Inquiry process allowed the analysis to identify, through carer narratives, the value of strong person-centred communication and recognise the requirement to build on this aspect of person-centred care. At times, this involved being the recipient of information, but it also involved being listened to, and professionals actively seeking out information from carers and people living with dementia. Nurses were more often identified as communicating in a person- centred way that ensured wellbeing and leading to carers having a positive outlook on the discharge process. Carers had a detailed insight into the ways in which poor communication could prevent person-centred care and undermine the personal worth of both the carer and the person living with dementia. Carers reported that being the recipient of poor communication was endemic within the hospital discharge process, and that this had a significant impact on their ability to prepare for the needs of the person living with dementia on leaving the hospital. Not being informed of changes in the patient's condition, or alterations required to the home to support the discharge, left carers struggling to manage the discharge process.

Katie: And the one thing, I think, actually, there was only one time that I felt so reassured, on, on one phone call from one nurse who actually, I think she rang me and just said, I'm looking after your dad and, I just want to get a bit of an insight into how he is with his dementia, and the penny dropped.

Somebody has the nounce to ask what kind of things he likes, what is he like and that? Like what upsets him? What's he good at?

Jack: It all boils down to a lack of communication or poor-quality communication, that would certainly help, and I would have liked to have had more information up front about what my wife's ongoing needs would be. It came as a bit of a shock to me because, as I say, prior to my wife going into hospital, you know she would go to the toilet.

Interviewer: And did anybody have a conversation with you about that or offer you any support when she was coming home?

Jack: No. No, no, no, if they could have helped to prepare me and said look, you know, your wife has become incontinent, or her condition has changed.

Several carers referred to feeling 'out of the loop' and felt that they did not have the relevant information needed to support the person they cared for. This led to complicated and distressing scenarios that could have been avoided through better information sharing. Carers felt that health and social care professionals were not forthcoming with pertinent information, and this led to carers feeling that they did not have a comprehensive overview of the discharge process or plan. Carers even felt that they were treated as an inconvenience at times. Being the recipient of poor communication could lead to long term financial difficulties resulting from the discharge, or immediate problems in relation to medication. Professionals did not discuss the impact of poor communication on the carer or person living with dementia.

> *Carol: People, people aren't always told that it's available. There are grants from the council that will help you modify certain bathrooms into wet rooms and, you know, have handlebars put in. It's all there but it has to be told, about because there's a lot of people out there that's struggling.*

Carers described demanding and even dangerous scenarios resulting from the lack of communication during the day of discharge. Sometimes there were legal ramifications, for example, deprivation of liberty orders being approved without relatives with power of attorney being informed, and only discovering this information at the completion of the discharge process through a third party. Experiences such as these, led to significant anger and emotional distress, undermining any experience of person-centred care.

> *Jane: She says, I bet you didn't know that the hospital, I bet you didn't know that the hospital put a dols on him?*
>
> *A deprivation of liberty order. I said 'no, I bloody didn't', and I, you know. And I said, 'well, we're lasting power of attorney over him'. So never mind. The final word as a family member like, and it's not like I would have opposed it. Of course, I wouldn't have, but it's like, well, you've got to involve the family.*

These dangerous scenarios reveal the absence of safeguarding, at times, for people living with dementia and their carers. I shall discuss this finding further in the next section.

7.2.3 Safeguarding as a pillar of person-centred care

It was apparent from the analysis that safeguarding the person living with dementia and their carer is a pillar of person-centred care, which indicates an integral regard for wellbeing. Health and social care professionals also stated that adequate safeguarding was a key stone in ensuring the wellbeing of people living with dementia and their carers. NHS England (2022b) defines safeguarding as 'protecting a citizen's health, wellbeing, and human rights', and it is this definition that I will employ in this section of the analysis.

Some professionals believed that they safeguarded carers by asking questions about their ability to care. However, carers identified multiple occasions where safeguarding did not occur during the discharge process. Carers were distressed and angry at the absence of safeguarding both for the person living with dementia, and themselves, and at the lack of consideration for both. Sometimes safeguarding was apparent, as in the example given by Elizabeth, who was asked when would be appropriate for her relative to be discharged, and who experienced a delay in discharge over a weekend to safeguard both herself and the person she cared for. This was appreciated as a sign of valuing carer and patient's personal worth. This instance is highlighted, in accordance with the Appreciative Inquiry method, as it details how safeguarding can be built upon with the discharge process.

> *Jack: At about three o'clock in the afternoon on Monday I had a ring on the doorbell. And then I went to the door, and lo and behold, there's my wife in a wheelchair with two transport drivers. And they knocked on the door and said, this is *** we've brought her home. And I was quite angry, because I mean, obviously, I was pleased, she was home. I asked them why I wasn't alerted to the fact that she was coming home, and the usual thing was, we had nothing to do with it, we're just following instructions.*
>
> *But what annoyed me was, I could have been out of the house. And, you hear some horror stories about people being left on the doorstep and things.*
>
> *Amy: Afterwards, a concern was the fact that they released an elderly 95-year-old lady with a broken hip and Alzheimer's, into the care of one individual. And that individual they made no, I mean, I've got arthritic knees, which makes things difficult and I'm having to go up and down the stairs, uhm like a jack in the box and*

> *umm but one person, and what if I had a heart [condition], I mean they didn't' ask me?!*

Related to an absence of safeguarding, health and social care professionals also described experiences of discrimination. These experiences shall be discussed in the next section of this chapter.

7.2.4 Discrimination

Some professionals identified that discrimination within the health and social care team could create a barrier to ensuring person centred care, and to maintaining the personal worth of people living with dementia during the discharge process. This discrimination was also felt within carer data, with some carers believing that health and social care staff perceived patients with dementia as 'extra work' (Shelly). Some carers identified that prejudiced beliefs about being unable to live independently in the community, led to care home discharges. This discrimination was viewed as devaluing both the personal worth of the person with dementia and the opinion of the carer. However, discrimination was not discussed by the majority of carers who attributed poor experiences of person- centred care to the hospital system or to a stretched service.

> *Specialist Dementia Nurse 3: Not all of the teams, but you do find sometimes that, the patient you know they might be 95, and been living really well at home. But there is still that stigma attached, if someone's had a hospital admission and how are they coping, or do they need 24-hour care?*
>
> *I think sometimes there's still that kind of quick, quick rushing and looking for 24-hour care placements. Rather than looking at how really restrictive it might be. So not always, especially when people have got a dementia diagnosis, there is still that stigma there.*

> *Shelly: They just weren't helpful. They just weren't helpful with her, I always feel like, is this ever going to change? Because people don't really tolerate dementia. And I'm being honest. I think its, forward staff, and this is wrong, but I think they, they see patients with dementia as 'extra work' compared to other patients, which is wrong. They actually said my mom was a wanderer, which she wasn't. And that really riled us. It's people's perception of what dementia is about.*

In this section, the Appreciative Inquiry approach enabled the identification that person centred care is vital to ensuring the personal worth of the person living with dementia and their carer, during the hospital discharge process. Person centred practices, involving positive communication, were identified as vital to ensuring the personal worth of carers and people living with dementia. These strengths must be built upon in accordance with the Appreciative Inquiry method. Further focus on ensuring adequate safeguarding, and the removal of discrimination was identified as important for supporting the wellbeing of the carer, and person living with dementia. In the next section, the importance of being treated as a care partner will be outlined.

7.3 Treated as care partners

Carers valued themselves, and the person living with dementia, being treated as joint care partners, and identified receiving such regard as crucial to their own wellbeing, and the wellbeing of their relative living with dementia. Being equitably consulted by professionals in relation to key decisions was a significant aspect of this. Consideration of the needs of the individual with dementia and their carer, was vital to feeling regarded as a care partner and this respect could help engender positive feelings of wellbeing. In accordance with the tenets of Appreciative Inquiry, this experience of being treated as a care partner can be identified as a potential strength of the process. The actions of individual professionals were identified as crucial in ensuing equality within the care partnership.

> *Elizabeth: One of the most well, I think one of the most exemplary things was when my husband was ready, medically fit for discharge. This was the Friday before the bank holiday, and the consultant on this ward just said to me, you know you can go home whenever you're ready. If you want to go home. As soon as, you think you've got the care package re- started. It's just one of the most trusting things, I think it really resonated with me.*

Conversely, not being treated as a care partner could have a detrimental impact on wellbeing. An unequal power dynamic resulting in carers feeling bullied within decision making or being dictated to during the discharge process was highly detrimental.

Carers also discussed their sense of being marginalised when challenging professional decision making, and the emotional impact of this.

> *James: I think the worst point for me, there, was being told that if you don't go along with what we want to do, which was take her to a care home. I said, I've got power of attorney, I'll just take her home and look after her, I've been looking after. They said, we will take you to court and overturn the power of attorney. This is the hospital!*
>
> *Jack: It was almost like, it's a fait accompli, by the way, she's coming out, you know. Bits of information was given to me, but I didn't feel I had much of a choice of what's going to happen. And what probably upset me to some extent was, I'd fought to try to get her out of hospital for so long. When I was kind of getting brushed off, you know. It's not, not happening,* ***we're making the decisions.***

It was evident from the analysis that professionals had a clear perception of the value of carers and people living with dementia as care partners. Professionals also identified that maintaining trust was significant in treating carers and people living with dementia as care partners. Working together towards shared goals was a key component of working in a care partnership for professionals. Ensuring decision making was shared between professionals and carers and people living with dementia in an equal tripartite formation, was identified as important within the partnership. The Appreciative Inquiry method enabled the identification of the value of working in partnership with carers and people living with dementia.

> *Consultant 01: She was discharged home from another trust. And then her son brought her to our trust because he lost all faith in the other trust. And it was things like, there wasn't a recognition that this lady was continent before she came in, and she came out of hospital, doubly incontinent, and the continence issue was never explained to the son. And actually, we've managed to get her continent of urine not bowel management, so it's, it's having that really good prior information. Um, to, assess what your goals are and what you're working towards.*

However, professionals acknowledged that there were times when carers and people living with dementia were not treated as care partners. There was an acknowledgement that choice was often not available within decision making, and that carers and people living with dementia are often overruled by professionals within the medical hierarchy. Financial constraints were also pinpointed as undermining the care partnership. The lack of choice cited by professionals reveals the absence of agency. This will be explored further in the next chapter of the findings, where the importance and facets of the third theme will be explored.

> *Nurse 01: We've referred to social workers to kind of, they're important for all, that she's said twice a day, or less.* ***But we've kind of taken that out with her hands now*** *and kind of said, I think three to four times is probably what you'll need.*

The value of ensuring the personal worth of the person living with dementia and their carer through an emphasis on person centred care, communication, adequate safeguarding and vigilance against discrimination, has been demonstrated as vital to ensuring wellbeing during the discharge process, within this section. The approach of the Appreciative Inquiry method has enabled the identification of these potential areas of strength within carer and professional narratives. The importance of being treated as a true care partner during the hospital discharge process has also been determined. Acting as a true care partner involves ensuring that agency is protected for both the person living with dementia and their carer. The facets of maintaining agency during the discharge process, shall be explored in the next chapter of the findings.

Chapter 8. Agency

In this section of the findings, I will discuss the importance of carers and people living with dementia maintaining agency during the hospital discharge process, and the ways in which the process can be empowering or disempowering. Four key subthemes were identified within the analysis; supportive professionals and interprofessional working enabling empowerment; empowering processes; contexts that enable equality and risk taking, and COVID 19 and the prevention of agency. Once again, within this section of the analysis the Appreciative Inquiry approach of identifying and building upon apparent strengths was utilised. It was evident that health and social care professionals believe that proactive individuals, across professions and the hospital community divide, were central to ensuring the agency and the wellbeing of carers and people living with dementia. The weaker aspects of the process are also detailed as it is important to acknowledge and learn from these also (Havens, Wood and Leeman, 2006). As in previous chapters, carer and professional perspectives are presented simultaneously to enable comparison. Table 16 outlines the agency themes and subthemes.

Table 16. Agency. Themes and subthemes.

Table 16
Theme 1 Supportive health and social care professionals enabling empowerment
Theme 2 Empowering processes
Subtheme 2.1 Disempowering nature of bureaucracy
Subtheme 2.2 Medication as a potentially disempowering factor in the discharge process
Subtheme 2.3 The empowering or disempowering process of planning the discharge process
Subtheme 2.4 The day of discharge and its potential to undermine the person living with dementia and their carer
Theme 3 Contexts that enable equality and risk taking
Theme 4 COVID 19 and the prevention of agency

8.1 Supportive professionals enabling empowerment

The benefit of strong, positive relationships and communication, between different health and social care professionals was evident from the analysis. Excellent teamwork between different specialist professionals was identified as crucial to ensuring solid discharge planning that ensured the wellbeing and agency of people living with dementia and their carers. It was identified as essential that specialist dementia teams are involved in the planning of the discharge process. Moreover, the role of the nurse as the central organiser in the discharge process was discussed, alongside the benefit of experienced professionals, and the input of the wider working team. Proactive professionals focused on planning the discharge process thoroughly were identified as important during the organizational process. These identified strengths were apparent throughout the Appreciative Inquiry influenced analysis process. The complexity of the organisational process was evident, alongside the need for enhanced skills and organisational ability from the discharging nurse. The data extract below reveals the attention to detail required by the discharging nurse to ensure that the discharge is organised efficiently.

> *Specialist Dementia Nurse 5: Our role is as a dementia care specialist team. So, part of that would be supporting the clinical teams in enabling them to, I suppose, look at that, the kind of correct, more support is in place at discharge, to see is the aim is for the person to go home or return back to their, the residence where they were admitted from.*

Carers had an awareness of the importance of interprofessional working, particularly between the acute and community settings. Elizabeth experienced fast and effective interprofessional communication, between the community and hospital sector, that ensured an efficient and positive discharge experience, and this was identified as a significant strength. By contrast, Jane felt that there was limited effective interprofessional working between the hospital and community. Carers focused on occasions where supportive professionals enabled them to care for their own and their relatives' wellbeing, and on occasions where professionals did not enable this.

Compassion was singled out as an important quality during the discharge.

Elizabeth: The consultant saw me in the corridor at 12 o'clock one day, when I got home from visiting that evening, I got a telephone message saying, 'I'm going to speak to the GP', because apparently the hospital at home team had to be referred to by the GP because that's another process. So, I got home in the evening, there was a message on my answering machine from the GP saying, 'I got an email from the consultant, could you make an appointment?' The GP is only around the corner, I popped into the GP'S at 8am the next morning to say the GP wants to have a word with me. The receptionist scheduled an appointment for later that morning. So, within 24 hours. I went back to visit my husband and the GP had spoken to the consultant again and within 24 hours, the consultant, the GP and me and the home care team plan had all been put into place.

Interviewer: That's brilliant

Elizabeth: So, my husband could come home that evening.

Jane: But like I said, I just got the impression it was red tape and it was the hospital saying he can be discharged from today or whenever, you know, imminently. I got the impression that there was no opening of channels of communication or what's the word? Negotiation about, well, can you keep him a bit longer? Or you know, this is this situation. It was just. You know it was there, there wasn't, there was no interprofessional communication.

Interviewer: And they're not communicating with one another at all?

Jane: Or with me. Yeah, so there you go.

Poor interpersonal relationships, or inconsistency with professionals, was characterised as problematic and detrimental to the agency of the carer. Engaging with a multitude of different social workers or district nurses was frustrating for both Katie and Carol, who both felt they could not build any relationships and were left repeating themselves to different professionals.

Katie: And that was extremely frustrating because I had to repeat over and over and over again, to a different person every day, what was going on, what help was needed in fact.

Carers discussed how the actions of professionals could leave them feeling undermined. Katie felt that social workers listened to her father, who lacked capacity, and other care professionals, rather than herself, which was frustrating as she believed she was best placed to know her father's needs and wishes. Carers specifically mentioned poor interpersonal skills, in relation to working and communicating with people living with dementia, as particularly detrimental to wellbeing when the person was being discharged home. Jack felt that carers with poor communication skills could act inappropriately, and potentially neglectfully, to his wife during personal care sessions.

> *Katie: the social worker had to go inside the care home and have a meeting with the care home manager to corroborate with what dad had just said and she was in there for quite a while. She came out, back to the car park and she said, well, I've had a long conversation with the care home manager, and she believes that your needs are being met fully here and she has concerns that you wouldn't settle in the new care home. Me dad actually had the best line going and he said, 'well, I'm a big boy now and I think I know where I'd be better'.*

While Health and Social Care Professionals were able to act in empowering ways, processes were identified as having the ability to promote or prevent agency for the carer and person living with dementia, and this shall be further discussed in the next section.

8.2 Empowering processes

It was found that the processes of discharge could be empowering or disempowering, and crucially, that they can safeguard or harm the wellbeing of people living with dementia and their carers. The subthemes identified included: the disempowering nature of bureaucracy; medication as a potentially disempowering factor in the discharge process; the empowering or disempowering process of planning the discharge process and the day of discharge, and its potential to undermine or support the person living with dementia and their carer. In accordance with the Appreciative Inquiry method, this section identified both the strengths and weaknesses of the hospital discharge process. Table 17 details the empowering processes subthemes

Table 17. Empowering processes subthemes.

Table 17
1 Disempowering nature of bureaucracy
2 Medication as a potentially disempowering factor in the discharge process
3 The empowering or disempowering process of planning the discharge process
4 The day of discharge and its potential to undermine the person living with dementia and their carer

Professionals had detailed insight into the processes that could support the agency and wellbeing of people living with dementia and their carers. Professional insight into the discharge process was often more nuanced and detailed, regarding the mechanisms of the process itself, than the insight of carers. Professionals identified that explicitly transparent processes, involving the multidisciplinary team and with the involvement of a discharge co-ordinator, alongside formal meetings involving carers, and the dementia specialist team are crucial to ensuring an empowering discharge process. These strengths of the process were evident using the Appreciative Inquiry method. Equally, professionals were critical of overly bureaucratic systems which could disempower both the individual living with dementia and their carer. The analysis of the data from professionals revealed that the discharge process itself was often taking precedence over the individual living with dementia and their carer. This can be identified as a weakness of the process (Reed, 2007). This section shall firstly consider the impact of bureaucracy on the ability of the person living with dementia, and their carer, to exercise agency.

8.2.1 The disempowering nature of bureaucracy within the discharge process

The cumbersome bureaucracy of the discharge process was singled out by both carers and professionals, as causing significant disempowerment for both the person living with dementia and their carer. High levels of bureaucracy led to difficulties for professionals within their own practice, which impacted on their ability to facilitate the agency of people living with dementia and their carers. Bureaucracy relating to communication between different local authorities and around different systems within certain services, was mentioned and understood as ‘red tape’ (Jane) which could be difficult for carers to navigate. Understanding the bureaucratic barriers themselves and learning how the system worked, was identified as time consuming and undermining the ability to organise an efficient discharge.

> *Elizabeth: So, he had to, my husband, had to change his GP from one borough to another just so that the district nurse could come in.*
>
> *But it's sort of things like that. You know, it takes a while to even understand what the issue is before you find out what the way round it is.*

Bureaucratic rules were a significant hurdle to ensuring a smooth discharge process. Rules regarding which services could communicate with each other were highlighted as a particular barrier to ensuring appropriate referrals, and adequate communication. The overt bureaucracy embedded within financial decision making was particularly disempowering, with the process for applying for finance arduous and often futile. Overly long, complex documentation relating to financial assessments was criticised as making the process opaque and taxing to understand.

> *Specialist dementia nurse 4: Well, so, because the discharge processes is managed by the hospital, social workers they can't refer to a day centre. So, then, we would have to do a referral to the community social workers to ask them for a day centre.*
>
> *Jack: So, they sent three files. I don't know if you have seen these documents. But one separate document, I think, is 45 pages long. And the explanation documents are another 20 odd pages, and I had no option but to print them out. They’re too long, I can’t read them on a screen.*

Alongside overly long and difficult documentation was the complexity linked to understanding medication schedules.

8.2.2 Medication as a potentially disempowering factor in the discharge process

The analysis showed that obtaining the correct medication was a challenging aspect of the discharge process. Receiving medication with little explanation and last minute, was heavily criticised by carers, and identified as causing significant complications at the point of discharge. Medication changes which were not explained to carers were identifiable frequently within the data. Some carers were astounded that people living with dementia could be discharged without prescribed pain medication, and with no explanation of the medications provided. Others described inappropriate medication in relation to continence being prescribed resulting in problems which later had to be addressed post discharge. Professionals acknowledged some of the problems related to medication distribution and how last-minute changes by medical staff could lead to confusion and delays. However, there was limited discussion of the medication distribution process from professionals, in comparison to carer narratives, suggesting a limited awareness of the negative impact on carers and people living dementia amongst health and social care professionals. Negative experiences were not universal, and the empowering nature of medication processes that considered the needs of the carer, and the person living with dementia, were evident in some carer narratives where integration between the community pharmacy and hospital pharmacy was praised. This was identified as a particular strength of the process.

> *Harriet: we had the discharge note with the medication and we had what was already in his medication draw in his dresser. And we were trying to reconcile them both. And at first, they couldn't help us but we kind of said look, this is a Friday afternoon, he's got to be sorted out for the weekend medications and they agreed to get somebody to ring me. Obviously, that took time, so you know we were sat, still sat on the floor, surrounded by the medication and some of the meds I was familiar with, like the diabetes medication but the heart failure medication I hadn't a clue. Giving somebody a huge bag of medication without any instruction is just not on.*

> *Interviewer: Did you have any kinds of issues with the medications, were the medications always quite well explained?*

> *Elizabeth: The medications were always very well explained, my husband was put on to insulin at one point and the district nurses and the hospital taught me how to do that, so I did that. the hospital pharmacists were very good at explaining the medication changes to me before discharge.*

Whether the medication was explained to carers adequately was related to wider issues concerning the strength of the discharge planning. This shall be considered further in the next section.

8.2.3 The empowering or disempowering process of planning the discharge process

The planning process of the discharge was heavily criticised by both carers and professionals, and the analysis of the data showed that the planning aspect of the discharge was central to delivering an empowering, or disempowering experience, for carers and people living with dementia. The discharge planning process was described as long and protracted for people living with dementia, involving significant assessment and paperwork. Utilising the Appreciative Inquiry approach and the need to Dream (Carter *et al*, 2007), professional participants identified that the discharge process could be better organised, with professionals themselves having a clearer understanding of each other's role and a more transparent timeline.

> *Specialist dementia nurse 3: For patients who are going into a completely new care setting, that's when things become protracted, so going to a new residential care home or intermediate care bed can all be quite a long process.*
>
> *Specialist dementia nurse 3: Yes, so lots of care facilities will ask for completed behaviour charts, completed nutrition charts and then we'll do the assessment forms. They have to be agreed by the hospital and shared with the family and agreed by the family, to make sure that we've identified everyone's care needs appropriately, then they have to go to a panel. They have to be agreed at panel around funding. And people who are self- funded there's more financial assessments to be done, and then we have to find availability in a home that somebody would choose to go to.*

It was identified in the analysis that professionals had a good insight into what enabled a 'good', functional discharge process that worked well. Operating the Appreciative Inquiry approach, Professionals identified the strengths of the process to include discharge meetings involving the carer, person living with dementia and multidisciplinary team, involvement of the specialist dementia team in the discharge planning process, planning from the beginning of the admission, and a designated discharge co-ordinator, with a single point of contact. Shared ward rounds and supportive technology were also particularly praised. The involvement of the specialist dementia team was characterised as enabling advocacy for the person living with dementia, and the identification and referral to services and support structures that could enable wellbeing in the community post- discharge. The role of the discharge co-ordinator in the process was particularly valued by professionals and identified as a strength of the process where available.

> *Specialist dementia nurse 3: And we've got a designated discharge coordinator for each ward. And they only do a rotation every three months. So, they get to know the patients as well as we do. They join the ward round every day. We have a ward round Monday to Friday. So, in that ward round, they can give the discharge update so everybody knows, and we've got quite a good patient information board that we can update as new information comes in, the OT can confirm delivery of equipment with the discharge coordinator, but also, you've got that one person who knows all of that information.*

Setting discharge goals with the involvement of carers, the person living with dementia, and the multi-disciplinary team were characterised as being very important. Working together to ensure a holistic portrait of the person living with dementia was considered vital to an empowering discharge process.

> *Specialist dementia nurse 1: It's really important to involve everybody. So, what we try and do it, so we have a weekly MDT on each of our wards, where we have therapists, the medical team, the nursing team, and the specialist. So, we have a really 'holistic view of the patient' and then normally either my job or the discharge team's job is to ring the carer to find out how they're managing, how they're coping. And how they see things in the future, because actually there's no point in that, in somebody up for discharge home, if the carer really can't cope with them coming home so. Yeah, and* ***you have to have a decision between all of you.***

The analysis showed that professionals characterised meetings as central to ensuring an empowering discharge process. Contrastingly, carers characterised meetings as having the potential to be profoundly disempowering. Many carers had never attended a discharge meeting or been offered the opportunity to attend one. Conversely, carers who had attended a well-planned, MDT discharge meeting had a fulfilling and empowering experience, which they believed had ensured a successful discharge. However, other carers detailed how they were undermined in the discharge meetings and felt that the professional staff, and discharge system, was actively working against them during this period of vulnerability. This reveals that strengths can be experienced as weaknesses for others, in correspondence with the social constructionist and Appreciative Inquiry approach. Therefore, it is important to seek multiple perspectives to give a fuller picture of a process.

Interviewer: So, there was a big discharge meeting and what kind of happened there?

Elizabeth: It was, the consultant convened it and it was a big inter-professional meeting and there was a physio and an OT, the consultant, and the ward sister. And somebody else and myself, and another relative and I say, that was my husband was significantly more diminished than he had been on admission and the consultant, an experienced geriatrician, was unsure that we would be able to manage at home, thought we should perhaps be looking at a nursing home. But he said he was prepared to let us try managing at home on the understanding that if he wasn't confident that we would be able to manage and I think if we'd had different calibre local authority carers, we might not have managed, you know. .....

Interviewer: It sounds like you had some good support and the discharge planning meeting, did you feel like it was kind of a two-way conversation as well, where you could kind….

Elizabeth: Oh yes. It was an experienced consultant who took on the views of the rest of the team. We also had a social worker there who I think was a good old-fashioned social worker who knew her stuff even, even, you know, coming home to start with, it, it. It was only after then when I realized, I compared my experience with the experience other people with having. I think it was, it was the initial discharge planning meeting. It was well planned [the discharge] and also, I think what was available to us, it was like a one stop shop.

> *James: And I was invited in, during visiting time in the afternoon, but in the morning and there were 8 people sitting in the patient visitors room and they were all to see me and 8 people felt that it was necessary to have 8 different experts in a room with me representing my mom, just to get it across to me that you're not bringing your mom home, she is going in a care home.*
>
> *Prior to the NHS job, I worked 16 years in legal aid. It's called inequality of arms. it's someone who can afford the best barrister against you acting in person.*
>
> *Luckily, I’ve had some experiences of dealing with this kind of situation before, but I thought afterwards in a quiet moment, I thought, how, if this is how they go on, how should that make other people feel, you know, I'm trying to cope with the fact that my mom's not coming home.*

In contrast to professionals, carers felt that there was little planning ahead of the discharge, particularly in relation to the date of the discharge. Some carers were sceptical that there was any detailed planning occurring even where there was a legal obligation, and others felt that if planning was taking place, it was taking place too late. If there was discharge planning occurring, some carers argued that it did not involve them.

> *Jane: And it's, you know, we hear about discharge planning, we hear about, you know all the kind of guidance about that and it's like, well, nobody planned his discharge from what I can see, and actually, you know, if even if somebody planned it, they didn't involve the multidisciplinary team that included social services in that if you see what I means, and they didn't bloody involve us.*
>
> *Me, little old me. Uhm, you know who has to live with this afterwards,*
>
> *Interviewer: Yeah, and the funny thing is when I interview professionals and you say, so what do you do to support carers? They say well from day one we involve them in the process. We make sure they're always involved in the process. We talk everything through and then we make decisions together and start planning for them.*
>
> *Jane: Bollocks [laughter].*

However, some carers did feel there was excellent planning occurring that was adequate and considerate of patient and carer needs. Admiral nurses were singled out by multiple carers as central to an empowering experience, although carers felt this might be due to the dedication and personality of the individual nurse. This suggests that good planning can enable an empowering discharge process for both people living with dementia and their carers. This highlight a strength of the process that can be built upon further in accordance with the Appreciative Inquiry method.

> *Michael: Well, you know, without the admiral nurse, to be honest, I wouldn't have, he was advising all the way through, and that was, that was that was great, and he called in once a week to see my parents.*

> *Interviewer: And what did you think was the best part of the discharge process, a part that worked really well?*
>
> *Elizabeth: I think it has to be the initial planning because, that's the comprehensiveness of the initial planning, is what got everything in place.*

The analysis showed that both carers and professionals believed that the planning of the discharge process was driven by finance and pressures around hospital bed availability and clinical staff availability. Professionals discussed their responsibility in relation to the management of public funds and the limited choices available to them during the planning process. There was also significant criticism of the ‘gap’ that was identified between the hospital context and the community, with carers describing a ‘hiatus’ (Harriet) of clear responsibility during this period. Carers discussed that not only did they often feel uninvolved in the discharge planning process but that the concerns of the process itself seemed to be dominating the discharge, rather than what they felt was vital to the process themselves.

> *Harriet: So, you know, there was quite a bit of hands-on help for him but you know that there is, I can only describe it as a hiatus that care of the hospital- to care in the community isn’t very good.*

> *Amy. And the thing they were obsessing over, when my mother was being released from hospital, I should say being discharged, seemed to be whether she could go upstairs….. I assumed that there would be a point when they would say, she will be released in the next ten days. These are your options. And if the option of a care placement had been raised, I would have gone for it, even though we would have to pay. There was no mention of anything*

> *like that at all. It was more about how high was the bed and how high is her chair when you sit on it?*

Professionals and carers disagreed significantly in relation to the discharge process during the pandemic. Professionals felt that the discharge to assess model introduced during the pandemic was a positive development within the process. However, carers had a contrasting opinion, and felt that the introduction of a discharge ward made communication, and obtaining relevant information, more complex.

> *Specialist dementia nurse 4: Randomly, I think the best features are that we aren't keeping people in hospital to do 1600 tons of paperwork, which then goes to panel and is either passed or not passed, and then it goes to brokerage while people look for a care home. For me it makes sense, they go to a bed to await a placement from the community, which is brilliant and is much, much better.*
>
> *Harriet: The discharge ward didn't know enough, because he hadn't been on there long enough for them to really get to grips with the situation. So, it's this thing of being on a phone and them re directing you back and forth to try and resolve it.*

It was apparent from the data that carers and professionals had conflicting views of the processes underpinning the discharge process. While it was clear that these processes have the potential to be empowering, many of the processes can be enacted in ways that disempower both the person living with dementia and their carer. This reflects the importance of reflecting, within the Appreciative Inquiry process, on the subjectivity of experience and that strengths of a process can also function as weaknesses. The day of discharge itself was highlighted as a potential source of disempowerment, and this shall be explored further in the following section.

8.2.4 The day of discharge and its potential to undermine the person living with dementia and their carer

The analysis revealed that professionals had a detailed insight into the organisation and multitasking required to ensure a smooth process on the day of discharge. However, they were critical of the way the day itself can be dictated by perceived bureaucratic processes, linked to the availability of care packages, service ‘pressures,’ and the added time pressure to complete the discharge. Professionals expressed a sense of frustration with the day of discharge itself and the difficulties of very last-minute organisation processes. Being extremely well organised was cited as crucial to ensuring success on the day of discharge when professional participants were asked to Dream of potential improvements to the discharge process.

> *Interviewer: On the actual day of discharge itself, what do you think are kind of the most important factors to make sure that that goes as smoothly as possible for the patient?*
>
> *Specialist dementia nurse 2: Everyone knows what's going on. So, the problem we have is social services will often only confirm packages of care the day that somebody is leaving. They can't always do that the day before, so, then it's always a bit of a rush to make sure family members know. Make sure heating is on, that somebody has access to a property, all of those things often can't, you know, if somebody's got certain medications, they can't. They can only be made ready on the day somebody goes home.*
>
> *So, for me, I think you know, the things that it would be really nice, if we had an extra 24 hours when we get that call to say everything's ready, just to prepare a patient, make sure they've got, you know, suitable outdoor clothing, making sure that somebody is, if they can meet them at the other end. Whereas however well we've planned somebodies discharge here until we've got that confirmation of the package of care. We can't send somebody home. ….*
>
> *But then because there are pressures, we're not in a position, once we know that, to keep a patient to the next day.*

The process on the day of discharge itself was particularly stressful and opaque for carers. Feeling rushed and disorganised was mentioned as a significant feature of the day. The lack of organisation, and last-minute nature of the process, led to a stressful experience for both carers and people living with dementia.

> *Amy: As I say, it all seemed a bit rushed. I found out around 1pm the day before that my mother was going to be discharged and it wasn’t a question of she’s going to be discharged, you have a choice of this that or the other, it was she’s going to be discharged and that’s it.*
>
> *So, on the day, it felt like people coming and going all the time, delivering things. You could hardly rest between visits. It was*

> *difficult making my mother comfortable because she had come home, and I was sort of dealing with people all the time. I was shocked at how frail she was, and I was shocked that they thought she was fit enough to come home, and to a home that no one had looked at.*

Transport was identified as particularly problematic by both professionals and carers. Professionals cited limited transport options as a source of delayed discharges. Carers found sourcing transport difficult and a source of conflict with hospital staff. The discharge letter was singled out as particularly disempowering by several carers and painted as being responsible for a number of difficulties during the discharge process. The lack of information pertaining to social care issues, or any information outside of the medical status of the patient, was highlighted as particularly disappointing. Another issue was the incorrect identification of the next of kin.

> *Specialist dementia nurse 4: And that we have to allow transport to get somebody out of the hospital in order to be home for the last care visit, or if they're going to a care home they have to be there before a certain time. And if there's a hold up in your transport that will all go totally pear shaped.*

The day of discharge could be a disempowering experience for carers and people living with dementia. Alongside this, concerns about risk could also lead to an absence of agency. This is considered further in the next section, which considers the importance of risk taking during the discharge process for people living with dementia and their carers.

8.3 Contexts that enable equality and risk taking.

Many professionals identified that a key barrier to maintaining agency and wellbeing was the excessive focus on the minimalization of risk within the discharge process. The Appreciative Inquiry method enabled the identification that a context which enabled risk taking, and therefore equality between the wishes of carers, patients, and the concerns of professionals, was vital to ensuring the agency of individuals and maintaining their potential for wellbeing during the discharge process. Professionals identified that this was an issue specifically for people living with dementia and their carers. The analysis showed that professionals often demonstrated a risk averse attitude towards the discharge process for this patient-carer dyad.

The dichotomy between ensuring safety and taking manageable risks, surfaced frequently in professional opinions of decision-making regarding discharge destination. Many professionals appeared to be stuck on the concept of physical safety as the primary concern within the discharge process. The concept of 'safe' (Nurse 01) arose multiple times within interview data. The person living with dementia being at risk of a potential fall was a prime concern for professionals, with concepts of safety being given priority above wellbeing and agency during decision making. The safety of carers was also given extensive consideration by professionals. At times, it appeared that coveting complete safety was prioritised above the wishes of people living with dementia and their carers. One nurse referred to safety concerns as a barrier, and it was clear that safety interests were used as justification for decisions made in relation to discharge destination, and the removal of agency for the carer and person living with dementia. Sometimes it was clear that concerns about risk and preserving safety were removing choice in ways that had a significant impact on the person living with dementia, such as taking away the option of using stairs.

> *Nurse 01: So, probably the lady who wants her husband home, while we said* ***it's not safe*** *like, I don't know how realistic her image of her husband is now.*

> *Occupational Therapist 1: Yeah, it is, I mean, there are obviously some stages where we have to make some best interest decisions, where the client's not able to assess the risk accurately for themselves. And may, their wish may be to still use the stairs because they're convinced, they can use the stairs, but in reality, they're no longer safe.*

Carers were critical of how decisions were made due to concerns around physical risk dominating wellbeing perspectives. Both professionals and carers recognised that concerns about the risk of falls could lead to decisions being made which supported a care home placement at the point of discharge. Some professionals were very critical of discharge decisions made in relation to the risk of falling that led to care home admission and felt that more risk should be tolerated to enhance the wellbeing of the carer and the person living with dementia. Conversely, some carers did interact with professionals who supported taking risks for the benefit of the carer and person living with dementia. Carers appreciated when there was a tolerance of risk during the discharge process due to the positive impact on the discharge outcome. Carers, such as Elizabeth, felt that tolerance of risk allowed her and her husband the chance to attempt a home discharge which was ultimately successful. This positive story of risk tolerance during the discharge process has been highlighted in accordance with the Appreciative Inquiry method.

> *Elizabeth: At what point the decision is made, what are the criteria for making the decision that somebody should no longer try and be mobile, mobilized and become either chair bound, or bed bound because it has a major impact on quality of life and health and wellbeing, because, you know, it has an impact on your blood pressure and everything. And I can see it from a pure health and safety, risk assessment point of view, health professionals have to make that decision. I didn't see any evidence of that decision being reviewed at any point.*

> *Specialist dementia nurse 3: I think we have a real issue with people not taking risks. Sometimes, I do think, take really big risks, because actually, you know, if that's something that the person, really, really wants but it probably won't work, I think we should still sometimes take that risk, because it's actually, it's really important to that person. And being at home in their own home, even if it was, the risk went to the point where they died, they might still be happier with that decision, than to be removed from their home and going to die in a care home.*

The reluctant attitude to risk taking amongst health and social care professionals was evident in relation to the pandemic. Professionals discussed how the prioritisation of safety within decision making, and the low tolerance of risk, led to decisions that did not prioritise the wellbeing of the person living with dementia, or their carer, or allow for agency. Professionals discussed how people living with dementia were being moved frequently to, ‘keep them safe’, from the pandemic at great detriment to their wellbeing. The pandemic context led to professionals expressing fears around their ability to adequately safeguard during the discharge process due to limited face to face contact. Professionals stated that they felt there needed to be a balanced approach between the risk of COVID 19 to the patient, and the benefit to their wellbeing of ensuring agency during the discharge process. The impact of COVID 19 on the agency of the person living with dementia, and their carers, will be considered further in the next section.

> *Nurse 01: Because of the pandemic, we can't allow visitors except for exceptional circumstances, whereby somebody is dying. And for patients with dementia, just because they've got dementia, we can't let a relative on the ward, which would be something which would be a comfort. Unfortunately, we are just trying to keep everybody safe.*

8.4 COVID 19 and the prevention of agency

Based on the analysis, it was evident that agency during the pandemic was understood to be significantly curtailed by both professional and carer participants. The continuously changing COVID 19 policy regulations (Department of Health and Social Care, 2020a) limited the degree to which carers, and people living with dementia could assert their independence within the hospital discharge process. The restrictions implemented around visiting were identified by both groups of participants as particularly preventative in relation to the facilitation of the discharge process. The data revealed the dominance of COVID 19 policy (Department of Health and Social Care, 2020a) concerns above the needs of people living with dementia and their carers.

In this section, I will outline how the policies related to the pandemic impacted on the ability of people living with dementia and their carers to exercise agency within the discharge process. This includes how the policy of no visitors in hospital impacted on the ability of professionals to build relationships with families and access important information about patients and carers, the impact of shortages of staff and equipment, the impact of Personal Protective Equipment, the experience of pressure to organise a quick discharge, an absence of community services in the pandemic, and the inability for face-to-face interprofessional working.

> *Specialist dementia nurse 2: Tends that you take much longer to get them back to what you think is a baseline but unless you've got that sort of interaction with carers, you haven't got that and then the support during the discharge process is just not there.*

The difficulties of appropriately organising the discharge process without the ability to consult with a wide pool of relatives and carers face- to- face were apparent. Some professionals discussed how this prevented personal relationships forming between health and social care professionals and carers, and how restrictions prevented a true understanding of the discharge circumstances. Other participants discussed how a dearth of visiting options meant that even autonomy around small aspects of the discharge process, such as clothing choices at discharge, was very limited.

> *Consultant 01: So, I mean it is getting a bit better now, but the visiting restrictions were really, really, hard and it's hard to plan a discharge if you've never met the carer.*
>
> *And I also think that health care, the provision of health care is significantly relationship based and it's really hard to develop those relationships with carers when you just can't see them face to face. So, we have seen an improvement in that, and it is easier now that some visitors can come in. But equally it used to be quite…. It used to be quite enlightening when you had more than the one visitor coming. Say, for example, you would maybe, have come, you know, you would maybe have, uhm, one daughter come in one day, a different daughter come in a different day, and each family member or each person who cares about that patient gives a little bit of the jigsaw.*
>
> *So, I felt that I had a better overview when I saw potentially multiple different people.*

Several professionals identified that there was an impact on physical ability caused by the absence of visiting and that this had a subsequent impact on the discharge options ultimately available. The impact on the ability to complete specific tasks necessary to move towards discharge was discussed by participants. Further to this, several professionals identified that the impact of restricted visiting was so detrimental to wellbeing that it was leading some patients to move towards end-of-life care, potentially prematurely. It was recognised that virtual visiting, including pet therapy and lunch clubs, could provide a limited substitute but that this option had substantial disadvantages for the autonomy and wellbeing of people living with dementia and their carers. Professionals recognised that virtual visiting prevented privacy and self-sufficiency and was not a substitute for face-to-face contact.

> *Specialist dementia nurse 3: Without any access to their loved ones, functionally, and sort of just the whole, you know, their whole well- being deteriorates. So, people have stopped eating and drinking, people have stopped wanting to get out of bed and people have expressed that they're given up and want to die.*
>
> *Specialist dementia nurse 3: People, you know, that [are} not able to come and see their relatives at the end of life, it's [tablets/laptops] been a good way of them to be able to, you know, have final messages and conversations and things like that, but you know that's not ideal.*
>
> *You know, you've got a 15-minute slot only. it's very difficult to leave somebody to have a private conversation.*

Carers also emphasised that the inability to visit complicated the discharge process thereby making it difficult to manage, particularly for carers unaccustomed to the hospital context, and not familiar with discharge. Being unable to physically meet with relatives living with dementia made complicated decision making, connected to discharge location, even more emotionally complex. For example, the absence of visiting meant that carers did not always know the physical and psychological condition of their relative, or whether they had deteriorated physically or cognitively. This reality meant that carers could be reluctant to accept the person living with dementia returning to their home, due to fears around a potential decline in abilities during the hospital stay. The logistics of aiding a relative, whilst being unable to visit them and assess their needs, was discussed at length by carers. The psychological pain of not being able to see a relative while they were at their most vulnerable in hospital, and potentially declining, was highlighted. Making decisions in relation to discharge to a care home setting was also made more complex by COVID 19 regulations (Department of Health and Social Care, 2020a), as carers had to tackle with the reality that they would not be able to visit their relative if discharged to a care home.

> *Carol: My mother in law was also worrying about the fact that she would have to do more around, the fact that she would have to do more hands-on care with my father-in-law, round personal care and stuff, until she was reassured that he was exactly able to do what he did before he went into hospital, so it's the fear of the unknown really and because I think he'd been in there for so many weeks. You don't know if she thought because, again, she couldn't be supported to do a zoom meeting and see him.*

> *There wasn't anything there, even a phone call for her.*

Difficulties obtaining relevant information about any potential decline in the mobility or health of their relative on the ward made carers feel powerless during the planning of the discharge process. Some carers expressed their frustration trying to access information from the ward, due to the restrictiveness of COVID 19 measures.

Another problem was caused by the limited access to relatives in acute settings due to restricted visiting. Attending meetings to discuss discharge options was very difficult for carers, and involved isolating before the meeting, lateral flow tests, and meetings taking place in unusual locations, such as within cars within car parks. Carers also discussed their confusion during the discharge process around COVID 19 isolation requirements. One carer was able to compare the multiple opportunities to support the person living with dementia in the ward setting and communicate with health and social care professionals through visiting in the pre-pandemic era, with the dearth of opportunities for these actions during the pandemic.

> *Katie: I said it isn't happening. I'm having a meeting with my dad, sitting next to my dad, so I can support him, because he's told me repeatedly and I am only repeating what he's been telling me to tell you himself. And I said, I am not having that meeting without my dad being present, so you know what had to happen and what happened. The social worker met with me in the car park. I was told that I had to do my lateral flow in the car park when I arrived. I had to sit my dad in the front seat of my car, and I had to sit on a chair in the car park and the social worker had to sit on a chair in the car park. She had to have a meeting with us, with my dad, with the car door open.*

> *Elizabeth: I've got a friend, friends, so they're in their 80's. She's frail but independent, her husband's, you know, in hospital again during the pandemic. And you know she's been looking after him at home during the pandemic, with lots of different admissions along the way, and it's just what you said about people not being able to get through to the wards and the communications not been there.*
>
> *Whereas, you know in my time, I would turn up on the ward at eight o'clock in the morning and they would welcome me in and give me the spoon and say- 'here's breakfast'. You know, you could…. Thanks for doing it, sort of thing, you know, but I mean. It's completely different now.*

Carers were left feeling helpless and unable to assert any agency during the discharge process due to their almost complete exclusion from the ward setting during the pandemic era. This led to them feeling uniformed, uninvolved, and unprepared for discharge.

> *Jack: Bear in mind when my wife went in, she could walk, she could talk and she was only urinary incontinence. It then became a challenge over the two weeks to, which is the length of time she spent in, to get information. And I was never able to go and see her. I was very concerned about what was happening to her, the treatments she was having.*

It was apparent from the analysis that it wasn't just the absence of visiting, and face- to- face meetings with carers, that was causing a deficiency of agency for carers and people living with dementia, but also the inability for professionals to meet and take part in face-to-face discussions. It was evident that this was preventing adequate discharge planning. Professionals in the social care sphere commented that they believed less joint working occurred due to pandemic regulations (Department of Health and Social Care, 2020a). An inability to visit home environments, or to implement capacity assessments face- to- face, was also identified as limiting for professionals.

> *Specialist dementia nurse 2: And then if there's any, then if there's any ongoing issues and socially…. They would be referred to the social worker. The social worker used to sit in the meetings, but I don't think they are now doing because of COVID.*
>
> *Interviewer: Yeah, yeah, and is that to just reduce contacts. And is that the same with relatives, did they sometimes used to come [along]?*
>
> *Specialist dementia nurse 2: Yeah, yeah, they used to, but not so much now UNLESS it's really complex. And it needs to be more of a family case conference but that that used to happen quite regularly, that the family came in. But kind **of COVID**, that that's reduced a lot now, so it's done via phone calls.*

Professionals identified the discharge to assess model, implemented during the pandemic, as both a positive change to the discharge process and problematic. The discharge to assess model was praised for speeding up the discharge process to allow assessment to take place within the community. However, the funding available to facilitate the discharge was only for the first six weeks of the discharge period. This led to scenarios where individuals and families were content to be discharged with funding, but when obligated to pay for the packages of care after six weeks, experienced failed discharges and a return to the hospital setting. The ability of carers and people living with dementia to make the right decisions and choices, in relation to discharge destination, was hampered by the push to discharge to the community as quickly as possible during the pandemic era. This left limited time to consider all available discharge options potentially leading to the detriment of the carer and person living with dementia.

> *Social worker 01: And you know, people, like, people inevitably are quite willing to accept the support once, if they know that they're not having to pay for it. But then, once they have to pay for it, then that changes. Quite often, not in every case, yeah. Quite often that changes, and whether they need that support or not. If their incapacitated and they feel they can't pay that contribution, then they will withdraw and then inevitably they'll come back at some point in greater crisis.*
>
> *Specialist dementia nurse 3: Almost the opposite of what I've just said that the push to get people out may override people going to the best place for them.*

The data showed that carers believed that staff shortages during the pandemic were having a significant impact on the discharge process. This was supported by interviews with professionals who cited that the obligation for their colleagues and themselves to isolate was affecting patient wellbeing. Staff shortages creating problems in accessing community care packages were considered particularly challenging during this period. Professionals emphasised how shortages in materials, and equipment, were also impacting on discharge plans, and the ability of carers and people living with dementia to maintain choice and independence in the process.

> *Abdul: I've been in a scenario where they've got enough beds, but they haven't got enough staff, some staff are on annual leave, some are off sick, or the agency staff haven’t turned up. And it's almost like one way to manage this is to release some of the patients. It’s like when they, when you go to see mum on the ward and they’re like, so your mom can go home and your like eh???*

> *Nobody told me that this morning, nobody told me that yesterday, nobody has rang me?*
>
> *Interviewer: And how has this affected staff with discharging and patients during COVID. Is it more difficult for you at the minute?*
>
> *Nurse 01: It can be to get, to get care packages, especially and I think this is because the community care is just stretched. So, you say, right, well, I need two carers for this person, four times a day. And then say okay, well, we can start, that in a week. And your like, well, that's a week that you've got this patient in hospital, who then can't go home.*

> *Consultant: Yeah, the other day in my rehab ward, the physio wanted to progress somebody onto a stick, but we were told there was a four-week waiting list to get a walking stick. Yes, and that's because of, there's been no mining over COVID of the raw materials. Then there's the shipping issues, the manufacturing issues, so there's significant pressures at the moment on equipment.*

Another significant issue preventing any meaningful agency, for people living with dementia during the pandemic, was the impact of PPE on their ability to understand and communicate with professionals. Carers with an insight into the communication difficulties experienced by their relatives were horrified at how difficult it must have been for their relatives to communicate with professionals wearing PPE.

> *Occupational therapist 01: I think, you know, somebody who, who's got a dementia and is confused, hospital is a confusing place anyway, and then not to see people's mouths and people's faces. And we just noticed that, you know, clients just tend to shut down a little bit and just it's too much hard work, so they'll just close their eyes and just shut down.*
>
> *Jack: I think it must have been horrific. I liken it to having been abducted by aliens and waking up on a spaceship and you've got all these strange people leaning over you, gowns on, visors on, wearing masks. And they're talking over you and it's probably muffled.*

The analysis showed that agency was curtailed significantly by the prioritisation of COVID 19 restrictions and regulations in the hospital setting during the pandemic (Department of Health and Social Care, 2020a), to the detriment of the person living with dementia and their carer. The inability of the person living with dementia or their carer to exert independence and agency within the discharge process, led to rushed discharges into the community setting following the discharge to assess model, which were hampered by the absence of face- to- face meetings, the inability to implement home visits or identify an appropriate care or nursing home. In summary, the barriers created by COVID 19 pandemic regulations made planning the discharge process very challenging and at times distressing, for professionals, carers and people living with dementia.

This section has outlined the findings of the analysis in relation to the importance of the ability of people living with dementia and their carers to maintain agency during the discharge process. The importance of supportive professionals, empowering processes and contexts that enable equality and risk taking were identified as supporting the maintenance of agency. In comparison, the ability of bureaucracy, medication, and the day of discharge to undermine agency during the discharge process was considered.

In the next section, I will outline the final section of the findings which utilises the Appreciative Inquiry process further, and asked the participants to Dream about the changes they believe would be beneficial for ensuring the wellbeing of people living with dementia and their carers. Carers and health and social care professionals are ideally placed to consider what changes to the process would enable wellbeing to be supported for this population due to their insights into the discharge process, and their understanding of wellbeing within this context.

Chapter 9. Dream

9.1 Introduction to Dream findings

This section summarises the specific changes that carers and professionals identified as being potentially beneficial to the discharge process, and which emerged during the Dream section of the Appreciative Inquiry analysis process. This aspect of the process moves away from focusing on the strengths and weaknesses of the discharge process to instead identify potential improvements. There are areas of overlap with other sections of the analysis, but it is important to the Appreciative Inquiry method to outline the specific changes, or dreams, that carers and health and social care professionals identified as desirable.

Carer and professional opinions were divergent, with carers having a much more detailed insight into the changes required to support wellbeing for both the carer and person living with dementia. Professionals often focused on changes that would be beneficial to their professional role such as improving paperwork processes. Carers had insight into wider changes that might be required in relation to the need for a national standardized system, with accountability for the discharge process, and the changes needed to support wellbeing for the carer and person living with dementia. Table 18 identifies the changes required to the hospital discharge processes noted by professionals and carers.

Table 18. Dream. Required changes to the hospital discharge processes identified by professionals and carers.

Table 18	
Professionals	**Carers**
Changes beneficial to the role of the professional:	Further respite availability factored into discharge process
Improved interprofessional communication particularly in	Extensive explanation of the discharge process, including

relation to the availability of a social worker	transport options and medication
Improvement in paperwork process	Significant explanation of the financial implications of different discharge process options
Additional care package availability in community, including additional support systems	Adequate signposting
	Further holistic involvement in the discharge process, including being given choices
Changes beneficial to the person living with dementia and their carer:	Further respite availability factored into discharge process
Further focus on the wellbeing of carers and people living with dementia	Meaningful communication replacing platitudes and inclusion of communication tools
Removal of stigma and discrimination from discharge process	Extensive explanation of the discharge process including transport options and medication
	Further education in relation to dementia for health and social care professionals
	Discharge assessment process to be community based
	More specialist dementia nurses to be available during the discharge process
	A national standard and procedure for discharge with accountability

9.2 Findings from Dream analysis

Professionals highlighted several changes they thought would be beneficial to the discharge process. They felt that further focus was required on the wellbeing of both parties, and the presence of additional adequate care and support systems in the community to facilitate this was important.

> *Interviewer: And what, what do you think, when you, when you are planning the discharge, what are the things that kind of help it to go well and to help it to be a positive discharge?*
>
> *Specialist Dementia Nurse 2: Making sure that the carers are getting the right level of support, because carer support are really good at knowing what's available on the ground, what services are out there and connecting with the carers.*

Professionals felt that often there was a rush into care packages or placements at discharge based on stigma and discrimination, concerning the physical and mental abilities of the person living with dementia, instead of holistically assessing the person living with dementia and enabling some agency and choice. Further to this, professionals expressed frustration at the limited care packages and support mechanisms in place in the community setting and felt that this context caused complications and delays in the discharge process.

> *Specialist Dementia Nurse 03: When people have got a dementia diagnosis, there is still that stigma there.*
>
> *Consultant 01: And they, they don't know why and sometimes that does happen and often with it on our ward, and it's because packages of care haven't come through.*

Carers agreed that there is a need for more support systems to be available to carers in the community, but their focus was for the provision of appropriate respite services primarily. Many carers discussed a need for more respite to be available, and for this to be factored into the discharge planning process.

> *Jack: So, I'm very fortunate that I made a connection with this carer, and been able to get somebody who can work more flexibly, and casually, and regularly, and just kind of come to an agreement with me, when I need them and, but I do wish that carers organizations had a pool of carers, paid carriers that you could book as and when required.*

Health and social care professionals also felt that some changes in the paperwork, and interprofessional communication, would lead to the improvement of the process.

> *Social Worker 01: I think, better communication between the health and social care. I mean, that that can always be improved in every situation.*

A ward based social worker was requested as professionals cited that some difficulties arranging discharges were due to limited communication with the social work team. Most professionals did not comment at length on what they felt could be better about the discharge process or appear to have a significant perception into what could be better for the carer, and person living with dementia. This was disappointing but one professional had some insight into a potential explanation for this, citing the pressures of the workplace leaving little time for professional reflection, in the context of significant funding pressures.

> *Nurse 01: Maybe have a ward based social worker, that you could go speak to, we're quite lucky in the fact that our physios and OTs are around. To get hold of the social workers, it's sometimes quite difficult.*
>
> *Social Worker 01: I think, sometimes, we can get a little bit blinkered and say well, you know, we're supporting with personal care, we're doing this, we're doing that, but actually the person is saying, but I'm not getting out as much as I, as I need to. We're not responsive to that, and that's because of the pressures, funding resource pressures. Obviously, it's limited, in what we can provide.*

Carers discussed changes they would welcome and that they believed would support their wellbeing, and the wellbeing of the person living with dementia, in much greater detail than professionals. On numerous occasions carers mentioned that they required someone to explain the discharge process to them and help them to understand the care and hospital system. The financial implications of the discharge process were also mentioned several times by carers. It was discussed that no-one had taken the time to explain the financial aspect of the discharge process, even though the financial implications of different discharge options are significant.

> *Michael: They're not going to do anything for me, you know, I think that what I would say is that, you know, somebody needs to make people aware of what the options are. And what are the financial support services available. And those sorts of things, because people just have to find their own way, through it.*

Understanding relevant professional roles, and what the process of discharge involves was something carers identified would be valued highly. More detailed signposting was also mentioned numerous times, with carers complaining that although certain services or modes of communication existed, they were of limited utility if they were not signposted to them effectively. The importance of meaningful communication was also mentioned numerous times, with carers decrying the platitudes often communicated via telephone. Carers demanded more analytical information be provided about the person with dementia’s physical and mental wellbeing, rather than the standard response of ‘slept well overnight, sat eating breakfast.’ There was also the request for more pro-active communication from professionals.

> *Carol: Uh, as far as speaking to him individually, again, until we got the number of a phone that could contact someone who knew him, uhm, you were only left asking somebody who would say, ‘oh yeah he’s fine, he’s sleeping at the moment’.*
>
> *Elizabeth: And nobody tells you what your options are, you know when you're booking transport, they don't say to you. No one says to take your own wheelchair into hospital is the most streamlined, well the most streamlined is to drive yourself to hospital with a blue badge, in a wheelchair accessible vehicle, but yes, it takes a while to work transport out, that sort of thing.*

Timings and the transport options were mentioned on several occasions as areas not explained well and causing significant stress on the day of discharge. More communication about the arrangements for the patient to come home was requested. Ensuring that the carer was adequately involved in the discharge planning process, and better education for health and social care professionals in relation to caring for a person living with dementia, were discussed as changes that needed implementing to ensure wellbeing. Being given choice around the discharge process, and tools to allow for adequate communication were requested. Several carers noticed that health and social care professionals sometimes did not have the skills or education needed to organise an appropriate hospital discharge for people living with dementia and their carer.

> *Jack: The discharge, right. I think, first of all, I should have been more involved in, in the timings etc, you could call or certainly, I should have been given, if you like better notification. Now, a simple thing would have been a telephone call to say your wife is getting into an ambulance in the next half an hour, not much simpler than that. Even a text message.*
>
> *Amy: First of all, I think someone should have come out and had a look at the house. And told me what needed to be moved to make things safer and talked to me about the realities of people coming out of hospital. I should have been given the opportunity to choose for my mother to go to respite before coming home and it was never even suggested. And I think they should have taken me into account and the whole situation and looked at who was caring for my mother and what would the pressures be on me.*

Carers identified that a change in the way discharge was assessed was required. Carers noted the difference in abilities and needs between a person living with dementia still in hospital and after discharge home. Carers requested that the discharge assessment should be ongoing, with vital assessments taking place in the home setting, rather than the hospital context. This occurred under the discharge to assess model implemented in response to COVID 19. More specialist dementia nurses were requested by carers due to their skill and insight into the challenges faced by the person living with dementia and their carer. A more holistic discharge system that took carer needs into account, and actively sought to include them in the process was requested by several carers.

> *Amy: It has been difficult. Individuals that I've dealt with have been really, really helpful and supportive. So, it's not the individuals, it's the system that's in place. It's not the people because when the physio comes out, they are really helpful. You*

> *know, they brought her a cup of tea and a wheeled trolley and sorted out an additional Zimmer for upstairs. Things like this, so, when they come they do get things done and but it's like the system, not individuals and that's the management isn't it*
>
> *It's a holistic approach that's needed isn't it.*

Several carers mentioned that they felt the discharge system needed radical overhaul. It was mentioned that policies and procedures needed to be put in place that centralised the needs of the carer, and the person living with dementia at the heart of the process, with some legislation in place to ensure accountability if this was not achieved. One carer felt that there should be a universal gold standard process developed, that all NHS trusts should adhere to, to ensure both quality and consistency within the discharge process. Carers were often shocked that there wasn't an explicit national framework for the discharge process for this patient and carer group, with an accompanying standardised set of operations.

> *Shelly: If I was diagnosed with cancer I would have a full team, I would have a Macmillan nurse. I would have a named nurse at the hospital. I would, you know, and it needs to be recognised as a terminal illness.*
>
> *That's what I'm trying to say.*
>
> *It isn't. It's how do we live with cancer, well, x y and Z.*
>
> *So how do we all live with dementia? Where's the policies, where's the protocols?*
>
> *There isn't any.*

It was evident from the Appreciative Inquiry analysis process, that there are numerous potential alterations to the discharge process that could be made to support the wellbeing of people living with dementia and their carers. Carers and professionals were united in their belief that more should be done to ensure wellbeing during the hospital discharge process. This included: more support for carers around finance and assessments; explanation in relation to transport; better communication; availability of policies and procedures; being adequately involved in the discharge process; being given choices; the presence of more speciality dementia nurses; and a more holistically focused process that values the needs of carers as well as people living with dementia. The impact of the Appreciative Inquiry process on data collection and analysis, facilitated the incorporation of the opinions of carers; and health and social care professionals, directly into the findings in regard to improvements to the process. The dream stage of the Appreciative Inquiry method lays the groundwork for the next stage of design, which aims to identify achievable changes to the process.

The findings have shown that there are many aspects to the subjective concept of wellbeing, but that supporting hope, personal worth and agency, are vital to maintaining the wellbeing of both the person living with dementia and their carer during the hospital discharge. I will now address how the analysis of the empirical data address's objective 2: identifying factors (environmental, organizational, resource or social) that ensure the physical, emotional and social wellbeing of patients living with dementia and their carers.

9.3 Factors that ensure the wellbeing of people living with dementia and their carers

The analysis has demonstrated the key factors that ensure the wellbeing of carers and people with dementia during the discharge process:

- **Proactive health and social care professionals and empowering processes that support carers and people living with dementia.**
- **Contexts that are supportive financially and in relation to care availability, and which encourage and allow for risk taking alongside consideration of physical needs.**
- **Consideration of needs beyond the physical, alongside person centred care that acknowledges the carer as a care partner and considers their needs.**

Additionally, cross-cutting features including **adequate communication and planning, appropriate safeguarding; limited bureaucracy, freedom from discrimination, transparent medication processes, and an appropriate day of discharge itself** are important factors that help to ensure the wellbeing of people living with dementia and their carers.

These findings help to develop the requirements specified, but not delineated, in the policy guidance outlined in chapter 3 (National Institute for Health and Care Excellence, 2015). These include the requirement detailed in section 1.5.15 that ‘the discharge plan takes account of the person's social and emotional wellbeing, as well as the practicalities of daily living’ (National Institute for Health and Care Excellence, 2015).

In the next chapter, the findings from the systematic review and empirical analysis will be integrated. The development of a framework generated from the findings to ensure the wellbeing of this carer dyad during the hospital discharge process will be presented.

Chapter 10. Integration of systematic review findings with empirical findings

10.1 Introduction to integration of findings

In this chapter I will integrate the findings from the systematic review analysis with the findings of the empirical study. I will discuss how the integrated findings have been used to begin the development of a framework aimed at ensuring the wellbeing of people living with dementia, and their carers, during the discharge process. By doing so, I will address the primary aim of the study and the first part of the secondary aim to expand the evidence base available to clinicians and policy makers in relation to this topic, and patient -carer dyad. The final section of this chapter will identify the relationship between findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data analysis and the systematic review synthesis.

The aim of this research was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. A secondary aim of the research included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group, during the hospital discharge process in the post COVID 19 climate.

The systematic review and empirical study were conducted separately but it is a useful exercise to consider how the two relate to each other. It is important to identify how the findings from the empirical project compliment or contradict the established literature in this area to demonstrate the value of this research project, and its addition to the evidence base available. This comparison of the findings of the systematic review and the empirical analysis was completed inductively by noting where the findings of the two research streams were cohesive, and where the findings diverged. The topic of wellbeing did not feature within the systematic review synthesis of the experience of people living with dementia and their carers, nor did the pandemic, and therefore, there is significant divergence between the systematic review synthesis, and the analysis of the empirical data which aimed to address this gap in the literature. Figure 10 depicts the development of the pandemic alongside my research project.

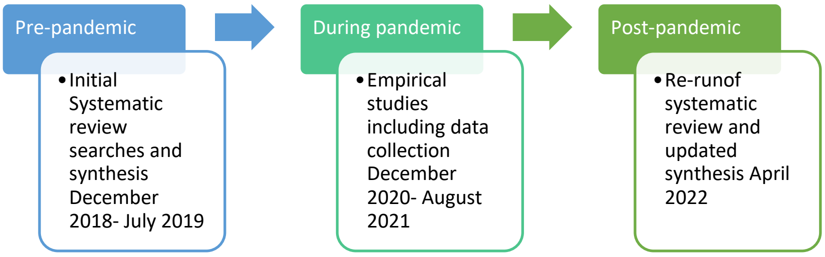


Figure 10 Pandemic timeline

I will identify how the empirical findings address some of the gaps apparent in the evidence base for this topic as revealed by the systematic review findings. I will argue that the findings of both the systematic review and the empirical study add to the wider body of evidence regarding the hospital discharge process for this group, and the topic of wellbeing.

The qualitative systematic review (outlined in chapter 2) aimed to answer the question: What are the experiences of people living with dementia and their carers, during the hospital discharge planning process? I utilised a meta ethnography method to synthesis the 36 studies that related to the carer experience and the 26 studies relating to patient experience following the re-run of the searches in 2022 (please see chapter 2 for further details). The findings from the synthesis for patients and carers are summarised in table 19 below.

Table 19. Systematic review themes relating to the synthesis of the experience of people living with dementia and their carers during the hospital discharge process.

Table 19
Systematic review themes relating to the synthesis of the experience of people living with dementia during the hospital discharge process
Theme 1: Patient undermined from taking part in discharge planning and decision making
Subtheme: Family members replacing patient in the discharge decision making process
Subtheme: Hospital system undermining ability of patient to have agency during the discharge process
Subtheme: Health and social care staff member's actions preventing patient involvement in the discharge process
Theme 2: Privileging of hospital requirements above patient centred care
Subtheme: Rushed discharge processes due to hospital requirements
Subtheme: Unsafe discharge practices due to hospital pressures
Theme 3: Absence of resource, policy and governance in the hospital discharge process
Subtheme: Deficiency in availability of community services
Subtheme: Lack of adopted discharge policy initiatives alongside ad hoc discharge planning
Systematic review themes relating to the synthesis of the experience of carers during the hospital discharge process
Theme 1: Carer experience of being included in the discharge process
Subtheme: Experience of being included in the discharge planning process (positive aspects)
Subtheme: Experience of being included in the discharge planning process (negative aspects)
Theme 2: Carers experience of being excluded from the discharge planning process
Subtheme: Not being treated as an expert in the care of the person living with dementia
Subtheme: Recipient of ineffective communication
Theme 3: Requirement for further robust support during discharge process

Subtheme: Unmet need for support for carer navigating the discharge process

10.2 Gaps revealed by the systematic review.

The systematic review revealed there was limited evidence on the following:

- Identification of how positive experiences of hospital discharge can be facilitated.
- How wellbeing can be supported in the discharge process.
- Identification of mechanisms to improve the hospital discharge process.

These research gaps informed the protocols for the empirical work and specifically, the topic guides for interviews. The topic guides for carer interviews sought to uncover the support carers identified as enabling the maintenance of wellbeing, elements of the discharge process that carers identified as functioning well and areas requiring improvement. The interview data, therefore, compliments the key findings of the systematic review to provide a more complete picture of the hospital discharge process. The decision to use an Appreciative Inquiry approach (Watkins, Dewar and Kennedy, 2016) facilitated this need to focus on positive experiences of the hospital discharge process which enable wellbeing.

Table 20 summarises the main areas of cohesion between the findings of the systematic review and the empirical study. Areas of divergence caused by the pandemic are also identified. The empirical data reflected many of key themes evident in the systematic review synthesis. The empirical study did not include patient participants due to the impact of social distancing and therefore, some of the nuances of the patient synthesis are not reflected in the empirical data. Several areas of disagreement emerged from the comparison of the systematic review synthesis and the empirical analysis. These included the value of formal discharge meetings, whether collaboration between professionals and carers is increased if there is a care home destination discharge and the status conferred on carers holding power of attorney. Table 20 details where the empirical data aligned with or diverged from the findings of the systematic review. Column A of Table 20 outlines the findings from the systematic review synthesis and column B identifies where these findings coincide or diverge from the findings of the analysis of the carer and professional empirical data.

10.3 Outlining cohesion between systematic review findings and empirical data findings and divergence caused by the pandemic.

Table 20. Cohesion between systematic review synthesis and empirical study findings.

Table 20	
Systematic review finding	**Empirical data finding**
1 Exclusion from discharge process for carer (Theme 1 in carer synthesis: *Experience of being excluded from the discharge planning process*) (Cox, 1996)	1 Identified within the subtheme *empowering or disempowering process of planning the discharge process* (Agency) Carers identified that they were not involved in discharge planning.
2 Lack of adopted discharge policy initiatives alongside ad hoc discharge planning (Theme 3 in patient synthesis: *lack of adopted discharge policy initiatives alongside ad hoc discharge planning*) (Coleman and Roman, 2015)	2 Identified within the subtheme *empowering or disempowering process of planning the discharge process* (Agency) Carers did not believe that adequate discharge planning was occurring.
3 Absence of Safeguarding (Theme 3 in patient synthesis: *lack of adopted discharge policy initiatives alongside ad hoc discharge planning)* (Bauer, Fitzgerald and Koch, 2011; Macmillan, 2016; Parliamentary Health Service Ombudsman, 2016)	3 Identified within subtheme: *Safeguarding as a pillar of person-centred care* (Personal Worth) The carer was distressed at lack of care shown to relative who was sent home unexpectedly in an ambulance.
4 The undermining of involvement in the discharge process from health and social care professionals and the	4 Identified within subtheme: *Supportive professionals enabling empowerment* (Agency)

hospital system itself *Experience of being excluded from the discharge planning process* (Theme 3 Carer synthesis) (Emmett *et al.*, 2014; Poole *et al.*, 2014; Telford, 2015)	Carers often felt undermined by actions of Health and Social Care Professionals.
5 Lack of clarity related to discharge process/policy (Theme 2 in carer synthesis: *Recipient of ineffective communication*) (Huby *et al,* 2004; Emmett *et al,* 2014; Kable *et al,* 2015)	5 This was evident within the analysis but tended to be conflated by participants with the *Uncertainty caused by the COVID 19 pandemic in the discharge process preventing hope* (Hope) and is identified within that subtheme.
6 Rushed discharge process (Theme 2 carer synthesis: *Unmet need for support for carer navigating the discharge process*) (Kaiser and Varghese, 2014),	6 Rushed discharge process were identified within the data but often associated with the pandemic and guidance to discharge quickly as identified within *COVID 19 and the prevention of agency* (Agency).
7 Inadequate community provision (Theme 3 in patient synthesis: *Deficiency in availability of community services*)	7 Carers and professionals identified inadequate community provision, but this was conflated with the impact of the pandemic and identified within subtheme: *Uncertainty caused by the COVID 19 pandemic within the discharge process preventing hope* (Hope).
8 Difficulty navigating community services (Theme 3 carer synthesis: *Complexity of navigating community services)* (Jamieson *et al.*, 2016; Gilmore-Bykovskyi, 2017)	8 Identified in the analysis by both Health and Social Care Professional participants but conflated with the impact of the pandemic: *Uncertainty caused by the COVID 19 pandemic within the discharge process preventing Hope* (Hope).
9 Ineffective communication (Theme 3 carer synthesis: *Recipient of ineffective communication*) (Bauer *et al*., 2011; Fitzgerald *et al*.,	9 Identified within the subtheme *Communication* (Personal Worth). Carers identified the impact of poor communication.

2011; Emmett *et al*., 2014 Sewter, 2014)	
10 Medication issues (Theme 3 carer synthesis: *Lack of adopted discharge policy initiatives alongside ad hoc discharge planning)* (Jamieson *et al*., 2016; Parliamentary Health Service Ombudsman, 2016; Gilmore-Bykovskyi, 2017)	10 Identified within subtheme *Medication as a potentially disempowering factor in the discharge process* (Agency).
11 Prioritisation of risk (Theme 3 carer synthesis: *Hospital system undermining ability of patient to have agency during the discharge process*. (Kadushin and Kulys, 1994; Mockford et al., 2017)	11 Identified within subtheme *Contexts that enable equality and risk taking* (Agency). It was evident that risk concerns were prioritised in the pandemic context.

Many of the issues identified from the qualitative synthesis were echoed in the findings from the empirical data. For example, the analytical finding from the empirical data that wellbeing is not prioritised for carers and people living with dementia during the discharge process agrees with the systematic review synthesis outlined in chapter 2 (Cumbler, Carter and Kutner, 2008; Bauer, Fitzgerald and Koch, 2011; Kable *et al.*, 2015; Deeks *et al.*, 2016).

Within the analysis of the empirical data, it was apparent that carers and people living with dementia continued to have the negative experiences identified in the systematic review. These experiences included being excluded from the discharge process (Cox, 1996), perceived ad hoc or absent discharge planning (Coleman and Roman, 2015), at times a lack of safeguarding (Bauer, Fitzgerald and Koch, 2011; Parliamentary Health Service Ombudsman, 2016; Macmillan, 2016), the undermining of involvement in the discharge process from health and social care professionals and the hospital system itself (Emmett et al., 2013; Poole et al., 2014; Telford, 2015), a dearth of clarity in the discharge policy and process, rushed discharge processes (Kaiser and Varghese, 2014), inadequate community provision and the inability to involve the person with dementia within the discharge process.

10.4 Identifying the role of the pandemic in the divergence between the synthesis and empirical data interpretation.

Difficulty navigating community services (Shippen, Young and Woods, 2011; Gilmore-Bykovskyi, 2017), ineffective communication and issues in relation to medication at discharge were all apparent in the empirical data in cohesion with the findings of the systematic review (Cumbler, Carter and Kutner, 2008; Kaiser and Kaiser, 2017). The impact of the pandemic in exacerbating these issues due to limited face- to- face contact was noted. The empirical data analysis also identified noted exceptions to these findings in agreement with the findings of the systematic review. These included that good discharge planning, which involves excellent communication, can enable a positive experience, leaving carers feeling that they were treated as care partners (Gupta *et al.*, 2006; Rhynas *et al.*, 2018).

The systematic review also revealed how ‘risk’ was often prioritised by professionals above the person living with dementia and their carer’s need for agency and choice (Norman, 2003; Huby *et al.*, 2004; Redwood, Eley and Gaughan, 2016). This identified finding played out during the pandemic in relation to infection control measures being consistently prioritised above maintaining wellbeing. From the analysis of the empirical data of this study, it is shown that rushed discharges due to hospital pressures were a feature of the early pandemic experience for people living with dementia and their carers. The subtheme identified in the third theme of the systematic review synthesis for carers of people living with dementia was overtly apparent during the pandemic period (complexity of navigating community services). The deficiency in community services became an absence of community services, as almost all were suspended for long periods during the pandemic, and being discharged without a discharge plan became standardised with the ‘discharge to assess’ model (Department of Health and Social Care, 2020b) formalised during the pandemic.

Many of the publications included in the systematic review addressing patient and carer experiences of the discharge process, focused on inclusion or exclusion in the planning process of people living with dementia and their carers (Cox, 1996). During the pandemic, this became almost a moot point due to the impact of social distancing and therefore, this finding is not reflected heavily in the empirical analysis of this research project. Although the absence of discharge planning was present within the empirical data, it was somewhat obscured by the wider impact of the pandemic. The discharge process during the pandemic was fundamentally dictated by social distancing policy decisions and face- to- face meetings, visitors to the ward, and other contacts were not allowed. Therefore, it was difficult for carers or people living with dementia to be truly involved in planning the discharge process (Department of Health and Social Care, 2020a). A rushed discharge process with hospital needs being placed above patient and carer wellbeing was prevalent during the COVID 19 pandemic. Safety and risk in relation to infection control were definitively placed above carer and patient needs according to the narratives within the empirical data of this research project. The analysis of the empirical data revealed that pandemic policy largely exacerbated problems already present within the discharge process as identified in the systematic review synthesis.

10.4.1 Divergence between the findings of the synthesis and the empirical analysis.

The systematic review synthesis demonstrated the value of formal discharge meetings (Cox, 1996; Gupta *et al*., 2006; Rhynas *et al*., 2018). Carers identified that formal meetings granted the opportunity for their opinions to be heard and to enable their involvement within the discharge process. However, the analysis of the empirical data revealed a mixed experience of discharge meeting for participants. Some experienced supportive discharge meetings which treated the carer as a care partner and others felt undermined by the meetings. This suggests that the value of discharge meetings may be fluctuating in different contexts. Cox (1996) and Telford (2015) identified that collaboration between professionals and carers increased if there was a care home destination discharge. The analysis showed that carers did not believe this to be true within the empirical data and that discharge destination made no difference to the interaction between carers and health and social care professionals. Coleman and Roman (2015) identified that there was a higher status conferred on carers holding power of attorney, but this was also not reflected within the analysis of the empirical data. Carer participants did not feel that there was any benefit bestowed on them through power of attorney and even felt this was at times ignored.

An area highlighted in the analysis of carer data but not prevalent in the systematic review findings was the importance of clarity regarding financial matters. In the analysis, carers frequently identified accessing finance overly bureaucratic and a source of stress, and yet this finding was not heavily reflected in the systematic review synthesis. The limited consideration of wellbeing in previous studies could explain why financial concerns have not been addressed within the research process. Processes were identified as a particular issue within the data of this study, more so than in previous research where involvement in decision making has often been ubiquitous. This may be due to the more prevalent role of processes during the pandemic period. In the empirical data it was evident that communication regarding the discharge was often curtailed to telephone contact, but this was expected during the pandemic. Therefore, while the communication by health and social care professionals was criticised, it was criticised less so than discharge planning. This may be because planning was identified as more important in pandemic conditions where opportunities to communicate were limited. Person centred care was not mentioned as frequently as would be expected in the empirical data but this may also be due to the limited opportunities to practice person centred care during the pandemic.

The empirical project focused on the topic of wellbeing and, in cohesion with the Appreciative Inquiry approach, aimed to identify ways in which wellbeing is, or can be supported within the discharge process. The empirical data analysis also aimed to identify the nuances of the factors that impact on the wellbeing of people living with dementia and their carers. This was not the focus or approach of the research included in the systematic review which was often aiming to identify problematic aspects of the discharge process. This may explain some of the differences between the synthesis of the systematic review data and the empirical data. The empirical analysis focused on where wellbeing is or could be supported within the discharge process, whereas the systematic review data was frequently focused on identifying negative experiences of the discharge process and areas for improvement.

As previously mentioned in the systematic review chapter (2), the review synthesis did not identify qualitative data relating to considerations of wellbeing specifically during the discharge process in the 2018 search. The 2022 search also did not highlight any research specifically focused on wellbeing for this patient and carer group during the hospital discharge process. Therefore, as previously identified it is possible that this is the only study that focuses on this topic during the pandemic. It is, therefore, an important addition to the evidence base in relation to wellbeing for this carer dyad during the hospital discharge process. The re-run of the searches in 2022 did not highlight any qualitative pandemic data regarding the experiences of carers or people living with dementia of the discharge process. Therefore, the findings of the empirical analysis represent an important source of in-depth data in relation to the qualitative experiences of this demographic during the pandemic. Research was implemented which examined the qualitative experience of wellbeing (Hanna *et al.*, 2022) for this patient carer dyad during this period, but without a specific focus on the discharge process.

This section has compared the areas of correlation and contention between the findings of the systematic review synthesis and the findings of the empirical data analysis. I have also identified areas where there is divergence due to the impact of the pandemic. In the next section of this chapter, I will outline the development of a framework to ensure wellbeing in the post pandemic period in answer to objective 5.

10.5 Framework to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Objective 5: Develop a framework, based on the perspectives of carers and healthcare professionals to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

Previously in this chapter, it was identified that there is limited evidence available in relation to wellbeing. Therefore, a framework focused on ensuring wellbeing during the discharge process, for both carers and people living with dementia, will have utility in the post pandemic period. Due to the diversity of experience, such a framework would need to be flexible and accommodating to both people living with dementia and their carers. Research by Ashbourne *et al.* (2021) has developed a theoretical framework for dementia-specific care transitions. This work expanded on the frameworks developed by both Naylor and Van Cleave (2010) and Hirschman *et al.* (2015) in relation to transitions of care. None of these models are focused specifically on hospital transitions, nor the maintenance of wellbeing during this period of the dementia journey. Therefore, the framework presented here enables the consideration of wellbeing to be considered alongside more functional frameworks.

Figure 11 represents a potential framework based on the findings of this research project. It has been designed in accordance with the socially constructed nature of wellbeing and the discharge process to enable flexibility and consideration of individual requirements. Although numbered 1-6, none of the areas take precedence over another. The numeration is designed to aid discussion and clarity of the framework. The findings from the Dream section of the analysis, developed through the application of the Appreciative Inquiry method were utilised in designing this framework. The findings from both the empirical analysis and review synthesis were also incorporated. The framework is not designed to be prescriptive but to provide guidance to professionals and policy makers about the key areas that professionals and carers identified as requiring reformulation to ensure wellbeing. Areas 1, 3, 4, 5, and 6 all align with recommendations in the policy outlined in chapter 3 (National Institute for Health and Care Excellence, 2015: Social Care Institute for Excellence, 2022). The next section of this chapter will now consider each of the areas of the framework. Carer and health and social care professional data was not always equivalent. Therefore, there are deviances in the findings across the analysis. The similarities and deviances are identified in table 22.

Table 21 represents the findings of the Dream section of the analysis and identifies the key areas professionals and carers would like to see change within the discharge process to enable the wellbeing of people living with dementia and their carers.

10.6 Dream analysis findings.

Table 21 demonstrates how the key findings from the Dream section of the empirical analysis relates to the framework. This section represents the ‘design’ phase of the Appreciative Inquiry cycle. Figure 11 depicts the potential wellbeing framework for people living with dementia and their carers during the hospital discharge process.

Table 21. Findings from Dream analysis.

Table 21	
Professionals	**Carers**
More focus on the wellbeing of carers and people living with dementia (1)	Further respite availability factored into discharge process (5)
Additional care packages availability in community including additional support systems (5)	Explanation of the discharge process including transport options and medication (3)
Removal of stigma and discrimination from discharge process (4)	Explanation of the financial implications of different discharge process options (3)
Paperwork improvement (3)	More signposting (3)
Improved interprofessional communication particularly availability of social worker (5)	Meaningful communication replacing platitudes and inclusion of communication tools (4)
Discharge assessment process to be community based (5)	Further holistic involvement in the discharge process including being given choices (2)
Greater tolerance of risk (2)	Further education in relation to dementia for health and social care professionals (6)
Requirement for process to place needs of carer and person living with dementia centrally (6)	Discharge assessment process to be community based (5)

	More specialist dementia nurses to be available during the discharge (5)
	A national standard and procedure for discharge with accountability (5)
	Carers to be listened to more (6)

Figure 11. Wellbeing framework

Each area has been mapped to the finding it represents. The areas included in figure 11 are outlined here.

1 Wellbeing as primary concern of discharge process that moves beyond only physical preoccupations.

This change will enable a holistic definition of wellbeing to take a central role. This is particularly important in relation to people living with dementia where research shows that physical wellbeing concerns can dominate discharge decision making (Emmett *et al.*, 2013). The analysis showed that concerns relating to physical safety could undermine other wellbeing areas, for example, requirement for respite. This requirement is identified in the available policy documentation (National Institute for Health and Care Excellence, 2016) but does not appear to be consistent within the discharge process.

2 Tolerance of risk in discharge planning

This will enable both carers and professionals and people living with dementia, to make decisions that enable wellbeing and tolerate risk. This change was requested by both groups of participants within the analysis.

3 Clear Road map for carer of discharge process (transparent processes)

Carers requested further transparent processes, as did professionals, particularly around social service input, and the day of discharge. The empirical data showed a requirement for further clarity for carers around areas such as transport home, medication, financial considerations, and the day of discharge processes. This level of planning is recommended by the policy discussed in chapter 3 (National Institute for Health and Care Excellence, 2015), but does not appear to be currently present in the process.

4 Carer and person with dementia as care partner with health and social care professionals

Meaningful communication, decision making, and the removal of stigma and discrimination were identified as vital to ensuring wellbeing within the empirical data.

5 Identification of adequate resources for carers and people living with dementia (accountability)

The need for adequate respite, the involvement of specialist professionals, care package availability and community re-assessment were all identified as vital to wellbeing. Carers requested more specialised nurse involvement and a national standardised discharge process (policy focused).

6 Centralisation of carer and person living with dementia in process from admission to discharge

Professionals ensuring that carers and people living with dementia are centralised in the process should be a priority. Carers requested adequate signposting and consideration of patient carer dyad needs.

In the next section, I will demonstrate in a table format the relationship between the systematic review synthesis findings, the empirical analysis findings, and the Appreciative Inquiry dream analysis findings.

10.7 How the findings from the empirical data and systematic review synthesis support the wellbeing framework.

This section of the chapter will demonstrate the configuration of the findings across the research project entire. This table incorporates the findings from the wellbeing framework (figure 11), the Dream section of the empirical analysis, the empirical data and systematic review. Table 22 demonstrates that there is support for the tenets of the wellbeing framework across all areas of the analysis.

Table 22. Cohesion across the findings of the systematic review and empirical data.

Table 22			
Dream Framework area	**Findings from professional interviews**	**Findings from carer interviews**	**Findings from systematic review**
1 Wellbeing as primary concern	Identified need for more focus required on the wellbeing of carers and people living with dementia	Identified a requirement for further focus on carer wellbeing and the wellbeing of people living with dementia. Move away from process centred discharge	Wellbeing is not the primary concern of the discharge process. Hospital processes and risk assessments often centralised.
2 Tolerance of risk	Some professionals supported	Further holistic involvement in the discharge	Concerns regarding risk often

	further tolerance of risk, but some did not	process including being given choices that include risk	prioritised above other areas
3 Road map for carer of discharge process (transparent processes)	Requested improvements in paperwork. Further clarity in relation to day of discharge and social service availability.	Further clarity required around transport home, medication, financial considerations and day of discharge processes	Further support required by carers navigating the discharge process
4 Carer and person living with dementia as care partner	Removal of stigma in decision making	Identified requirement for more communication and shared decision making	Requirement for more communication and signposting
5 Identification of adequate resources for carers and people living with dementia	More resource availability in community. Further interprofessional communication with social worker.	Further specialist nurse involvement, standardised discharge policy	Requirement for adequate community resources. Carers often facing long waiting times or absent services
6 Centralisation of carer and person living with dementia in the process from admission to discharge	Process to be driven by carer and patient needs and not hospital concerns	Carers to be listened to more within discharge process	Being involved in decision making

Table 22 reveals the detail of how the wellbeing framework is supported by the findings across the research project. Although there is diversion in specific detail, there is cohesion in each section of the wellbeing framework. Each section of Table 22 illustrates how the framework is supported by the empirical analysis findings and the systematic review synthesis. In the next section, I will consider the utility of the wellbeing framework further, and the value it may offer in re-focusing the discharge process onto the topic of wellbeing. I will also consider the relationship of the framework to available policy.

10.8 Discussion of the wellbeing framework for people living with dementia and their carers during the discharge process.

The framework represents a significant change in relation to the primary language utilised during the discharge process. In a previous section of this chapter, it was mentioned that a significant transformation in language usage and discharge focus is required to enable a shift towards wellbeing as a priority. This shall now be developed further. Person centred care has been the dominant term for care which is holistic and individualised, and is considered the gold standard in dementia care. However, since its inception, it has been identified that 'person-centred care' lacks clarity and definition in terms of clinical practice and is often not being implemented effectively (Edvardsson, Winblad and Sandman, 2008; Clissett *et al.*, 2013). Although the seminal work by Kitwood (1997) has immense value and was revolutionary in transforming how people living with dementia are conceptualised and treated, the term person centred care has arguably never had a precise meaning within the sphere of clinical practice. This has limited its impact and obscured its true purpose and meaning. Certainly, many of the participants of this study were not experiencing 'person centred care', even if that term was frequently being utilised in interviews with professional participants.

It could be contended that the word *care* itself shifts the focus towards the idea of physical 'care' within the discharge process. This is misleading and tends to mean that carer needs are overlooked. In contrast, wellbeing as a new concept can be defined by carers and people living with dementia themselves. It has the capacity to operate as a much broader term which enables it to be individualised to encompass many different social, physical, emotional, and economic areas. A shift in terminology, while challenging to introduce in practice, would not be impossible and there are historical examples where this has been successful, including the classic example offered by person- centred care itself (Kitwood, 1997). Such a shift in language offers the opportunity for a different outlook on the discharge process for carers, people living with dementia, and health and social care professionals. Person-centred care should remain an important concept within the discharge process due to its emphasis on the person, as in all areas of dementia care, but the term wellbeing offers an opportunity for further preciseness of meaning.

In the post- pandemic period, there is an argument that a new emphasis on wellbeing can allow a radical change in the discharge process itself. Post- pandemic there is a requirement for change in how the discharge process is constructed to pull back from the medicalised structure (Degerman, 2020; Goldberg, 2021) that has operated during this period, and been driven by infection control measures instead of person-centred measures. The Appreciative Inquiry process advocates that there are moments when changes in ideology and terminology can be introduced following seismic alterations in events, and the COVID 19 pandemic represents such as occurrence. The introduction of the Health and Care Act (Department of Health and Social Care, 2022c) represents a time of change. The utilisation of this framework may support such a change within the discharge process to enable a new focus on wellbeing. Although existing policy, (National Institute for Health and Care Excellence, 2016) outlined in chapter 3, explicitly requires health and social care professionals to consider the wellbeing of the person living with dementia and their carer, it was clear from the empirical data analysis and systematic review synthesis, that this is often not happening in practice. The requirement for extensive planning and considerations of wellbeing that move beyond the physical (National Institute for Health and Care Excellence, 2016; Social Care Institute for Excellence, 2022) were also identified within existing policy in chapter 3, but the findings of this research project reveal that there is a need for a framework to achieve these ideals in practice.

10.9 Summary

This chapter has compared findings from the systematic review and empirical data. A potential framework to support wellbeing during the discharge process developed from a consideration of the analysis findings across the research project has been outlined. It is acknowledged that it requires further development alongside carers, professionals, and people living with dementia to ensure its applicability and validity. In the next section of this thesis, I will discuss the findings of this research project in relation to established literature and outline the strengths and limitations of the research project, wider implications and further required research.

Chapter 11. Discussion

11.1 What this research project has achieved and the definition of wellbeing within the context of the hospital discharge process.

In this chapter the ways in which the findings of this research project expand what is known about wellbeing for people living with dementia and their carers, during the hospital discharge process, will be presented. I will discuss the key findings of the empirical research project including how the findings align with wider academic literature, how a social constructionist stance enables a nuanced understanding of wellbeing and the value of the Appreciative Inquiry process in identifying changes required to promote wellbeing during the hospital discharge process.

The impact of neoliberalist policies (Mooney, 2012; Schrecker, 2016; Becker, Hartwich and Haslam, 2021) and the impact of COVID 19 on wellbeing during the discharge process will be considered. Implications of the findings of this research project for local NHS trusts, local councils, clinicians, and relevant charitable organisations, such as Alzheimer's UK, will be presented. Towards the end of the chapter the strengths and limitations of the research project will be considered and recommendations for future research made.

At this point I will revisit the aims, objectives, and research questions of the research project. The aim of this research project was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process in both the pre and post COVID 19 contexts. A secondary aim of the research project included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group in the post COVID 19 climate. This included developing a definition of wellbeing within this context using the Appreciative Inquiry approach (Cooperrider and Fry, 2020).

More explicitly, the introductory chapter identified the objectives which included:

1. Conducting a qualitative systematic review to identify and synthesise available evidence regarding the experiences of people living with dementia and their familial carers, during the hospital discharge process. *What are the experiences of people living with dementia and their familial carers, during the hospital discharge planning process?*

2. Identifying factors (environmental, organizational, resource or social) that impact the physical, emotional, and social wellbeing of people living with dementia and their carers, during the hospital discharge process, through interviews with health and social care professionals and carers.

3. Exploring if and how the wellbeing and support needs of adults living with dementia, and their carers, are addressed in current hospital discharge practice or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

4. Identifying how guidance from 'COVID 19 hospital discharge requirements' (Department of Health and Social Care, 2020a) impacted on the discharge process during the COVID 19 pandemic.

5. Developing a framework, based on the perspectives of carers and healthcare professionals to ensure wellbeing in a post pandemic period, during the hospital discharge planning process, for people living with dementia and their carers.

The research questions of this project included: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers? What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?*

The following sections of the chapter will discuss the findings of the research project. The corresponding objectives were achieved alongside answering the research questions. Objectives 1 and 5 were addressed in the previous chapter and will not be discussed in this section. I will begin by discussing the definition of wellbeing in the discharge context for this patient-carer dyad which addresses the research question: *How can wellbeing be understood and defined during the hospital discharge process for people living with dementia and their carers?*

11.2 Defining wellbeing within the hospital discharge process.

As discussed in chapter 1, the rising profile of the concept of wellbeing within health care policy, and particularly within policy in relation to the hospital discharge process, requires that wellbeing is defined adequately. Rich qualitative data is required to enable policy makers to understand what wellbeing represents for people living with dementia and their carers during the complex hospital discharge process (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016; Department of Health and Social Care, 2020a). This became more important during the COVID 19 pandemic when the Department of Health and Social Care cited the concept of wellbeing in their guidance, within the first six months of the pandemic. It is also appropriate to consult health and social care professionals in their interpretation of wellbeing, as their practice is key to ensuring that policy concerns are achievable in practice for carers and people living with dementia (Harvey and Kitson, 2015).

Wellbeing has been recognised as a socially constructed term (Dodge *et al.*, 2012; La Placa, McNaught and Knight, 2013) and reductive definitions are not useful in this context due to the diversity of meaning for different individuals. This research project has aimed, with the assistance of the Appreciative Inquiry approach, to identify some of the tenets of wellbeing to illuminate the field of wellbeing in this context, in a manner that is meaningful to professional and lay stakeholders. There have been previous attempts to define wellbeing for people living with dementia and their carers (Tyack and Camic, 2017; Stansfeld *et al.*, 2017). Cunningham, Cunningham and Roberston (2018) attempted to identify a definitive definition but were thwarted by the diversity of understandings of wellbeing. Research has attempted to identify extrinsic and intrinsic factors (Stansfeld *et al.*, 2017) for a definitive definition. The definition presented here is specific to the discharge process and is not an attempt to codify a wellbeing definition that can be applied objectively or outside of this context.

The combination of the Applied Thematic Analysis and Appreciative Inquiry methods enabled the incorporation of Kitwood and Bredin’s (1992) wellbeing theory into the definition presented here. The importance of defining terms used frequently policy documentation has been discussed widely in numerous sectors to ensure appropriate policy implementation (Iezzoni and Freedman, 2008; Martin and Cobigo, 2011). This definition incorporates the diversity of perspectives from clinicians and carers in cohesion with social constructionist understandings (Berger and Luckmann, 1991). In the introductory chapter, I identified that the UK Government defined wellbeing broadly as including 'physical, social and emotional dimensions of wellbeing' (Department of Health, 2010). The analysis presented in this thesis builds on this broad definition significantly.

Definition: Wellbeing during the discharge process is the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond. Agency is comprised of *processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking*. Hope is defined by *moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers*). Personal worth is comprised of *ensuring person-centred care and being treated as a care partner*.

Identifying and delineating a definition of wellbeing in the discharge context represents an important source of information for clinicians, policy makers and stakeholders. Working with limited information concerning what defines wellbeing or similar terms, impacts upon how policies are devised, actioned in practice, and even understood by stakeholders themselves (Grant, Parry and Guerin, 2013; Rodriguez Santana *et al.*, 2021). It is hoped that the findings of this research project will contribute to greater understanding of how wellbeing can be supported during the discharge process for both carers and people living with dementia. It is understood that working towards a definition is only the first step in this process. Applied research must take place in response to this definition that explores how practical clinician actions, and actionable policies in the acute and community sector, can work towards achieving wider wellbeing. It is also accepted that agency, hope, and personal worth are subjective terms and can be interpreted in different ways by carers and people living with dementia. This chapter will now explore how the findings of the empirical analysis integrate with existing literature in this topic area.

11.3 Discussion of empirical findings and existing literature.

In this section, I will consider how the findings of the empirical study integrate with wider literature regarding the care for people living with dementia, wellbeing, and the hospital discharge process. The discussion of the empirical study findings and their relationship with established academic literature will follow the format of the themes that emerged from the empirical analysis, namely, the content of the themes: Hope, Personal Worth, Agency, and Dream. The factors identified in chapters 5, 6, 7, 8, and 9 in response to objective 2, and in answer to the research question: ‘What are the factors that support the wellbeing of people living with dementia and their carers during the discharge process?’ are discussed within this section in relation to wider literature.

11.3.1 Hope

The theme of Hope revealed that although some health and social care professionals had insight into the experiences and emotions of carers, and people living with dementia, many did not. Therefore, there is a requirement for health and social care professionals to have insight into the requirements of people living with dementia and their carers, that moves beyond considerations of physical wellbeing during the discharge process, to ensure the maintenance of hope. This is not a new finding within the wider literature as caring for people living with dementia and their carers in a manner that considers emotional wellbeing is established both in the academic world, and in the policy documentation considered in chapter 3 (Kitwood, 1997; National Institute for Health and Care Excellence, 2015; Korstjens and Moser, 2018).

The deficiency, identified in the empirical analysis, of emotional support available to carers is unfortunate in the light of the guilt carers described experiencing regarding care home admission. This circumstance has been previously identified as an aspect of the discharge process requiring the provision of further emotional support (Kadushin and Kulys, 1994; Cox, 1996; Bloomer *et al*, 2016; Jamieson *et al.*, 2016). Recent research by Gallego-Alberto *et al.* (2021) has shown that guilt associated with care home admittance remains stable over time. This indicates that there is a need for support in relation to care home discharge destination to be available to carers throughout the discharge process. As early as (2000), Shyu called for a service that supported the mental health and wellbeing of the carers of individuals living with dementia during the discharge process, including in relation to managing emotions and decision making around discharge destination. Other research by Davis *et al.* (2011) has shown that psychosocial support for carers after care home admittance can reduce the burden of guilt for carers over time. The findings of the analysis of the empirical data reveal that there is still a requirement for more robust emotional support for carers, during the discharge process, than is currently available.

The study by Jamieson *et al*. (2015) indicated that support groups for carers online could be a useful source of emotional support during the discharge process which would allow carers to connect with peers and manage their emotions. Further to this, a recent online review has shown that online support groups can be effective in supporting the wellbeing of carers of people living with dementia (Etxeberria, Salaberria and Gorostiaga, 2021). Therefore, it could be argued, based on the findings of this research project, that there is a growing body of evidence detailing the need for more resources to support the emotions present related to the discharge process, with the potential for these to be offered online.

The finding within the theme of Hope that stress, particularly in relation to medication and the day of discharge, had a significant impact on the maintenance of wellbeing is also established within the literature (Cumbler, Carter and Kutner., 2008; Kaiser and Varghese, 2014; Kaiser and Kaiser, 2017, Sawan *et al*., 2021). The findings from the study by Coleman and Roman (2015) indicated that carers are often overwhelmed by the medication schedule at the point of discharge, and this was also identifiable within the empirical analysis of this research. Sawan *et al.* (2021) suggested that there should be further integration between hospital and community pharmacists and GPs, with carers directed to a key community pharmacist for advice and support at discharge. Other researchers, such as Walker *et al.* (2009), have supported the introduction of a discharge specialist pharmacist within the hospital and found that this led to fewer medication errors. The findings from this analysis would support an approach that increases access to pharmacists for carers during the discharge process, to avoid the negative experiences of medication on the day of discharge that were evident within the empirical analysis, particularly during the pandemic.

The theme of Hope revealed the importance of ensuring that the needs of people living with dementia are met relating to activities, hobbies, and social outlets. Kable *et al*. (2015) identified that there was often failure to consider social requirements within the confines of the discharge process, and the findings of this study reveal how important it is to consider these less tangible needs of the person living with dementia and their carer. Related to this finding is the need for respite to be considered for carers during the discharge process to enable the continuation of social activities and hobbies that ensure wellbeing. This lack of consideration was a particular issue for both Jack and Amy, who might both have benefited from respite inclusion. Respite has been acknowledged as vital to all carers and particularly those caring for individuals with dementia (Neville *et al.*, 2015). It has been identified in established literature that a significant barrier to respite is both availability and carers not being signposted appropriately to respite facilities (Phillipson, Jones and Magee, 2014; Neville *et al.*, 2015). These studies have not considered the value of respite for the carer being factored within the discharge planning process but only when the person living with dementia is situated within the community. The findings of this study expand upon the importance of respite within the literature to include its value during the discharge process, and not just during periods where the individual is living within the community.

The importance of admiral nurses for the maintenance of hope during the discharge process was outlined by multiple respondents within the data. The admiral nurse is a relatively new introduction into the nursing sector (Bunn *et al*. 2013) but has been identified as increasingly valuable in ensuring the wellbeing of carers in previous literature (Maio, Botsford and Iliffe, 2016). However, an evidence synthesis by Bunn *et al.* (2016) showed that while valued by carers, there is little evidence of the impact of admiral nurses and their role can vary dependent on the needs of the area. There was no evidence available within the systematic review relating to the value of admiral nurse support within the discharge process. This may be because admiral nurses are traditionally based within the community setting and therefore, not integral to the discharge process itself. The findings of this analysis develop the evidence base in relation to what is known about the role of the admiral nurse and the utility of the support they can provide during the hospital discharge process. The role of the admiral nurse should be re-evaluated to consider their worth in relation to the discharge process in the light of these findings. Further integration between community services and acute sector services has been called for within recent policy documentation, and this finding adds further weight to this (Department of Health and Social Care, 2021; NHS England, 2022a).

In the next section, I will consider how the content of the theme Personal Worth intersects with established academic literature.

11.3.2 Personal Worth

An important finding of the empirical analysis was that person-centred care was defined differently by carers, and by health and social care professionals, in relation to the discharge process. Person centred care, often referred to as patient centred care, can have different meanings in different contexts and this has been acknowledged previously within wider literature (Gillespie, Florin and Gillam, 2004). Gillespie, Florin, and Gillam (2004) identified that 'patient centred care' is defined by different professionals in different ways and is dependent on the context and objective of the professional role. Edvardsson (2015) identified that the absence of a shared definition of person-centred care in specific contexts can be problematic. However, this problematic issue has not been discussed previously in the context of the discharge process for people living with dementia and their carers. Therefore, it is an important finding of this study that person centred care must develop a specific definition within this context. The analysis of the empirical data yielded the following potential definition within this context: positive and adequate communication, adequate safeguarding, and an environment free from discrimination. This definition requires further verification, expansion, and development with the aid of people living with dementia as it currently lacks this necessary dimension. Interestingly there is no mention of 'getting to know' the person living with dementia (Kitwood, 1992) and tailoring care accordingly. This may be due to the restrictions of the pandemic context.

Both the systematic review synthesis and findings from the empirical analysis highlighted that poor communication has a detrimental impact on the personal worth and wellbeing of both the person living with dementia and their carer. The empirical analysis also revealed how the language used during the discharge process reflects the inherent power hierarchy of the patient/carer health and social care professional dyad (Goffman, 1961). The empirical data showed that spoken communication for health and social care professionals was often focused on the one-way communication of information from the health and social care team to the carer and patient to ensure clarity. Although often framed as discussions, language choices revealed that the professional participant viewed themselves as the active communicator and the carer or patient as the passive partner. Terms such as 'allow' used by health and social care professionals, in relation to patient or carer activities, reveals this power imbalance. Whilst multiple studies have considered how carers and people living with dementia are undermined during the discharge process (Coleman & Roman, 2015) none have specifically explored how the language used is perpetrating this.

The inherent danger of poor communication leading to dangerous or illegal situations was identified within the existing literature (Poole et al., 2014; Boaden, 2016; MacMillan, 2016). The report by Boaden (2016) identified that limited communication, leading to last minute discharges, created potentially dangerous scenarios for people living with dementia. This was reflected in the experiences of the carers who took part in this study and were not given advance warning of their relatives' discharge date and time. Emmett *et al.* (2014) identified that it was often difficult for carers to safeguard people living with dementia during hospital discharge due to limited communication from health and social care professionals. The repeated absence of appropriate safeguarding for the person living with dementia was identifiable across multiple studies included in the systematic review (Cumbler, Carter and Kutner, 2008; Kaiser and Varghese, 2014; Kable *et al.*, 2015; Deeks *et al.*, 2016; Parliamentary Health Service Ombudsman, 2016; Kaiser and Kaiser, 2017). Kable *et al.* (2015) found that safeguarding of the person living with dementia was often overlooked, particularly in relation to communication connected to medication. The empirical data from this study expands this established finding further as it is not just the person living with dementia who is left unsafeguarded by the lack of communication, but also the carer themselves. This was particularly apparent in the data from both Jack and Amy who were both distressed by the lack of adequate communication which led to an absence of adequate safeguarding.

The role of discrimination within the discharge process was not explicitly addressed during the systematic review synthesis. The role of discrimination in relation to people living with dementia is well established within the literature (Herholz *et al.,* 2002; Milne, 2010). Milne (2010) discusses how being diagnosed with dementia leads to a perception of having lost autonomy and the ability to make decisions, and outlines some of the ways this can be challenged. It was somewhat disturbing to discover that professionals still felt discrimination was playing a significant role within discharge decision making. This finding was not matched within the narratives provided by carers which suggests it may be covert and potentially invisible to carers and people living with dementia. Previous research has pointed to education and role modelling in practice as the key mechanisms to overturn such discrimination (Chan and Chan, 2009). It is important that this analysis has identified the need for the discharge process to be included in training programmes aimed at counteracting discrimination against individuals living with dementia.

The empirical analysis showed that being treated as an expert care partner was vital to ensuring wellbeing for the carer and the person living with dementia. This builds on the findings of previous research which identified this requirement within the discharge process (Bauer et al., 2011a; Mockford *et al*., 2017). Telford (2015) and Bloomer *et al* (2016) found that not being treated as an expert care partner led to an experience of disempowerment for carers and the findings of the empirical analysis develop this further. Both James and Shelly referred to being actively bullied by professionals within the discharge process. No previous study has suggested this level of potential malignancy within the discharge decision making process, and this worrying finding should be further investigated in future research projects to explore whether it is a deviant finding or a more prevalent experience.

Another significant finding of the analysis of the empirical data was the clarity of professional insight into how to treat a carer and/or person living with dementia as a care partner. Professionals identified shared goals, trust and shared decision making as crucial to ensuring that carers and people living with dementia are treated as care partners during the discharge process. Much of the research in this area is focused on areas for improvement within practice or experience primarily (Macmillan, 2016; Mockford *et al*., 2017). Therefore, this finding is helpful in developing what is known about the professional insight into being a care partner during the discharge process with people living with dementia and their carers. It is also an encouraging finding as it demonstrates that health and social care professionals have a good insight into the actions needed to ensure a positive care partnership and that they were implementing these insights within their practice.

11.3.3 Agency

It was evident from the empirical findings that proactive and supportive professionals are key to ensuring the continuance of agency in the discharge process for people living with dementia and their carers. The value of proactive individual practice is a known phenomenon within dementia care and was evident within the systematic review synthesis. (Cooper and Deeks, 2012; Deeks *et al*., 2016). For example, Deeks *et al.* (2016) specifically found that individual professional practice was linked to adequate medicine management at discharge. The dementia champions programme has been designed based on an awareness of the value of proactive professionals in influencing quality of care for people living with dementia (Jack-Waugh, Ritchie and MacRae, 2018). The dementia champions programme trains professionals in hospitals to specialise in the care of people living with dementia in their practice area. These programmes are often focused on the 'care' aspects of the treatment received by people living with dementia during their hospital stay. This study shows that there is also applicability in relation to the discharge process and ensuring that professionals are cognisant of the positive impact proactive care can have on the wellbeing of individuals who are leaving hospital.

One finding of the empirical analysis was in relation to the prioritisation of physical risk undermining agency. This finding was also evident within the synthesis of the systematic review (Kadushin and Kulys, 1994; Schreiber, Powell and O'Dowd, 2018; Rhynas *et* *al.*, 2018; Hall *et al.*, 2020). Poole *et al.* (2014) found that considerations around risk was often undermining the right of people living with dementia to make their own decisions. Huby *et al.* (2004) found that stringently narrow definitions of risk and risk assessments were being applied broadly and undermining the agency of the person living with dementia and their carer. However, Schreiber, Powell and O'Dowd (2018) identified that this barrier could be overcome if professionals prioritised aspects other than just physical safety. The analysis of the empirical data revealed that both professional participants and carers were in favour of the prioritisation of physical risk being challenged to ensure holistic decision making. This is an encouraging finding as both participant groups agreed on this point suggesting that there is scope to explore this further in future research projects.

Another finding of the empirical data was the detailed professional insight into the processes that ensure agency for people living with dementia and their carers during the discharge process. Professionals used their experience and expertise to identify transparent processes, involving the multidisciplinary team (MDT) and a discharge co-ordinator, alongside formal meetings with carers and the dementia specialist team as crucial to ensuring the agency of people living with dementia and their carers. Jamieson *et al.* (2016) and Gupta *et al.* (2006) identified the importance of the MDT and involving carers in decision making but the specific value of a ward-based discharge co-ordinator and transparent processes were not identified in the systematic review synthesis. Other research has identified the value of the discharge co-ordinator in relation to the discharge process generally (Day, McCarthy and Coffey, 2009) and policy guidance (chapter 3) also recommends the presence of a discharge co-ordinator (National Institute for Health and Care Excellence, 2015). The findings of the empirical study suggest that further research to evaluate the value of a discharge co-ordinator during the hospital discharge of people living with dementia is required.

An area of conflicting narratives between the empirical data of the participant groups was in relation to discharge meetings. Meetings were presented as both vital in supporting agency (Elizabeth) and entirely disempowering (James/Jack). This conflict was also identified within the systematic review synthesis (Cox, 1996; Gupta *et al*., 2006; Emmett *et al*., 2014; Rhynas *et al*., 2018) and suggests that there is a requirement for further research into the value of the discharge meeting itself and the factors that enable it to aid people living with dementia and their carers to maintain agency. Discharge meetings have been acknowledged to function differently in different contexts (Waring, Marshall and Bishop, 2014) and further codification of the steps required to ensure a successful and empowering discharge meeting is warranted.

In this section I have reflected on how the findings of the empirical research intersect with wider academic literature in this area. Divergences with established literature were outlined and the contribution of new evidence from this research has been identified. In the next section, I will consider how the findings of the research project align with a wider critical discussion of the inequality of people living with dementia and their carers.

11.4 Alignment of the research project findings with the wider critical discussion regarding the wellbeing of people living with dementia and their carers.

Objective 3: To explore how the wellbeing and support needs of adults living with dementia and their carers are addressed in current hospital discharge practice or whether wellbeing requirements are currently overlooked and if so, why they are overlooked.

Objective 3 aimed to evaluate how wellbeing is addressed within the discharge process and whether wellbeing requirements are currently overlooked and if so, why. The answers to these questions are complex and driven by numerous organisational, structural, and personal factors explored in the findings of the empirical study, including individual professional practice, the absence of transparent discharge policy and the pressure exerted on inpatient and community services. The findings of this research project reveal that the medical model of illness and medical hierarchy within the institution of the hospital, are still the dominant forces within the discharge process for people living with dementia and their carers (Goffman, 1961; Engel, 1977). The empirical data analysis and the systematic review synthesis showed that carers and professionals felt that the discharge process was often being driven by financial considerations, pressures on bed availability and clinical staff availability. It is also evident that the strength of these constructed paradigms was exacerbated by the COVID 19 pandemic and its regulations.

Considerations of risk and decision making driven predominantly by health and social care professional interests, appear consistently in the empirical data across both participant groups. Although policy is clear that the wellbeing of people living with dementia and their carers should be central to the discharge process (National Institute for Health and Care Excellence, 2015), it is evident from the findings of this research project that this is often not happening in practice. This finding was not unexpected, as previous research has pointed to this conclusion (Mockford, 2015; Mockford *et al.*, 2017). This finding also aligns with wider academic critical gerontological discussions in relation to older people within society and particularly, older people living with dementia and the discrimination and stigma they face (Townsend, 1981; Holstein and Minkler, 2007; Van Dyk, 2014). A version of this narrative has played out across the pandemic. Older people have been objectified as 'vulnerable' and positioned as largely to blame for social distancing restrictions needed to protect them in their 'vulnerable' status. Other academics have explored this representation and critiqued how it has been exploited throughout the pandemic (Lichtenstein, 2021; Silva *et al.*, 2021). Silva *et al.* (2021) identified how ageist assumptions and prejudices manifested in relation to resource allocation during the pandemic. The same prejudices were discussed explicitly within the data regarding the reluctance to refer people living with dementia for rehabilitation during discharge due to the assumption that they would not be suitable.

In chapter 3 it was identified that the policy available before the onset of the pandemic (National Institute for Health and Care Excellence, 2015; National Institute for Health and Care Excellence, 2016) required that professionals must consider the wellbeing of people living with dementia and their carers during the hospital discharge process. The findings from the analysis of the empirical data identify that wellbeing is overlooked during this process. The policy discussed (National Institute for Health and Care Excellence, 2015) also required that hospital discharge should be a well-planned process which places patient and carer needs above internal pressures. The fulfilment of this requirement was sometimes evident within the analysis of the empirical data but carers frequently reported experiencing no discharge planning at all. In chapter 3, I stated that following the analysis of data from the empirical study I would identify whether the 2016 quality standards (National Institute for Health and Care Excellence, 2016) are being upheld in practice. The analysis would suggest that the standards are not being upheld. However, the pandemic setting of this research project may not be representative of standard practice and therefore, there is scope for further research in this area to clarify this further.

11.5 Comparison of findings with other recent research in this area

A recent study (Reeves *et al*, 2023), using data from the Hospital Episodes Statistics datasets for England 2010/11, 2012/13 and 2016/17 and analysing over 5 million hospital discharges identified that people living with dementia have a 30% increased risk of death within thirty days of discharge, in comparison to people living without dementia. The authors suggest that this may be linked to an inability to recognise when a person living with dementia requires palliative support, rather than acute treatment. Alternatively, there is a suggestion that it may be linked to people living with dementia being discharged inappropriately, or without the correct community support in place.

Further to this, the authors identified that although many initiatives to improve the experience of people living with dementia during their hospital stay were implemented during this period, no improvement in outcomes was identified. The authors consider whether this may be because outcomes are influenced less by hospital culture, and more by service availability, for example, staff shortages, limited community social care resources and the pressure to free up beds.

This conceptualisation was reflected in the findings of this thesis. Staff shortages during the COVID 19 pandemic and significantly curtailed social care service availability in the community, were identified as impacting negatively on the discharge process by health and social care professionals. The pressure to ‘free up beds’ was also identified by carer participants and health and social care professionals, who lamented the impact of this pressure on their ability to plan the discharge process effectively and in a person-centred way. The data used in the Reeves *et al* (2023) analysis did not include pandemic data and therefore, does not reflect the period and experiences of the participants of this study.

However, the findings of this study argue that by adopting a focus on wellbeing and what can support wellbeing in the hospital environment, there may be a way to improve patient experience. This was a perspective supported by participants and professional interviewees. The social constructionist approach suggests the value of changing hospital culture to being wellbeing focused, in contrast to linking poor outcomes to service and staff availability only. It could be argued that if there is an absence of focus on wellbeing and supporting wellbeing, even with greater staff availability and service provision, nothing will change or improve. The authors (Reeves *et al*, 2023) also identify that data regarding patient experiences, including of the discharge process, was not captured in the Hospital Episodes Statistics datasets. Therefore, the findings of this study reveal the perspectives of carers regarding the discharge process and add to what is known qualitatively about this process.

11.6 Social constructionist understanding of the discharge process.

The discharge process should place the needs of people living with dementia and their carers at its heart according to available policy guidance (National Institute for Health and Care Excellence, 2015). The experiences discussed by participants within this research project suggest that health and social care professionals are often placing the concerns of the hospital and social services system centrally instead. This is evident from professional participant focus on the risk of falls predominantly and the pressure to discharge quickly, particularly within the COVID 19 guidance (Department of Health and Social Care, 2020a). Within this guidance (Department of Health and Social Care, 2020a) there was a pressure to discharge quickly, even when the action was inappropriate for the carer and person living with dementia. This finding relates to wider concepts regarding the inequality people with dementia and their carers experience (Herrmann *et al.*, 2018). Further to this, one could argue that the position of this carer-patient dyad is being socially constructed within the discharge process as a reflection of their wider position within society (Townsend, 1981; Swaffer, 2014; Eisenberg, 2009). This aligns with the theoretical concepts outlined by Foucault (1973) in relation to the power structures created by institutions, which ultimately position patients below the needs of the institution itself. Furthermore, it supports the tenets of theorists who suggest that language is used to support hierarchies, through terms such as risk, which ultimately underpin the dominant concerns of the institution (Derrida, 1970).

The theoretical concept that risk is utilised as a mechanism to support the concerns of the institution above the needs of the individual, corresponds with the findings of the synthesis of the systematic review. Norman (2003) and Rhynas *et al.* (2018) both found that the opinions of health and social care professionals, regarding concepts of risk, were elevated above the opinions of carers and people living with dementia. This ultimately undermined the patient/carer dyad influence on the discharge process.

This finding was mirrored within empirical data where bureaucracy was also a barrier undermining the influence of people living with dementia and their carers. This suggests that people with dementia and their carers are not valued within the discharge process to the same degree as the value placed on the system itself. This would complement Berger and Luckmann's (1991) concept of shared common worlds which thrive through externalisation, objectification and subsequent internalisation, for example, of concepts of risk that ultimately disempower people living with dementia and their carers while supporting the needs of the hierarchy. This imbalance between the value of the process and the value of the patient/carer dyad needs to be addressed urgently if policy which supports the prioritisation of wellbeing is to be upheld in hospital discharge practice (National Institute for Health and Care Excellence, 2015).

A social constructionist approach would suggest that there are several ways this can be achieved (Camargo-Borges and Rasera, 2013). The process of leaving the hospital is constructed between the actions and dialogue of carers, health and social care professionals and people living with dementia themselves (Harding and Palfrey, 1997). Therefore, changing the discharge process involves re-thinking and re-imagining the procedure to centralise wellbeing for people living with dementia and their carers. This is an approach supported by the empirical data, as both carers and professionals were in favour of further focus on the wellbeing of people living with dementia and their carers, than is currently present within the discharge process.

One potential solution is for assessments and decisions to be re-constructed to focus primarily on wellbeing with the carer and person living with dementia being positioned at the centre. This was something carers requested in the empirical data. Face- to- face meetings immediately after admission, where carer and patient opinions are regarded as of equal, or even more importance, than medical concerns would change the landscape of this process. Good examples of this were revealed by the experience of Elizabeth who felt her needs and concerns were prioritised by health and social care professionals. It is important to learn from the negative experiences of carers such as James and Shelly. A change in language usage to move away from words such as risk and safety and towards words such as enablement and empowerment would be required to support this change in how the process is understood and co-ordinated. The professional participants of the empirical study suggested that these changes would be feasible and supported in practice. Furthermore, these changes would be supported by the tenets of Foucault (1973) and Derrida (1970) and enable the character of the discharge process to change significantly. This would represent a substantial change, not necessarily in the discharge process as it stands, but in its emphasis. All these potential alterations are supported by the findings of the analysis of the empirical data of this research project and underpinned by the systematic review synthesis findings.

A change of this magnitude would need to be implemented in many ways as indicated in guidance to facilitate change issued by NHS England (2013). A shift in policy towards centralising wellbeing instead of merely addressing it (National Institute for Health and Care Excellence, 2016) would represent a step forward. The development of a framework to ensure wellbeing during the hospital discharge planning process for this patient/carer dyad represents a first step to achieving this change in emphasis. The framework developed within this research project is a natural conclusion to the findings identified through the Appreciative Inquiry approach of the empirical project and the systematic review synthesis. This section has considered how the findings of this research project echo the wider academic discourse regarding the positionality of people with dementia and their carers within society. It has also considered how a social constructionist understanding of the discharge process could lead to a change in focus towards wellbeing. In the next section, I shall consider the findings of the Dream section of the empirical data analysis and how the findings relate to wider academic literature.

11.7 Discussion of Dream section findings

In this section, I will discuss how the findings of the Dream segment of the analysis intersect with wider academic literature. During interviews both professionals and carers were asked to Dream (Cooperrider and Whitney, 2005) about improvements they believed would benefit the discharge process. This is an important aspect of the Appreciative Inquiry process as the expert knowledge of participants regarding the strengths and weaknesses of a process is identified. Carers requested more information and support during the discharge process regarding the financial implications of their decision making. The significant financial impact of a dementia diagnosis (Alzheimer's Society, 2023) and the increasing carer financial burden has been discussed in recent literature (Bayly *et al.*, 2021). The findings of the empirical analysis suggest that further information regarding the potential costs of different discharge options should be available during the discharge process for the carer.

Further signposting was requested by carer participants. The importance of adequate signposting and the impact of not receiving appropriate signposting has been identified previously, although not in this context (Hagan, 2020). The need for further signposting may indicate a role for the dementia care navigator within the discharge process (Bernstein *et al.*, 2019). Dementia care navigators are currently a community support service with a limited evidence base (Bernstein *et al.*, 2020). Further integration between hospital services and the community-based care navigator service may offer the possibility of providing the signposting services requested by carers. Further integration may also address issues identified in relation to transport if care navigators are able to signpost potential options.

The request of health and social care professional participants to re-introduce ward based social workers echoes a recent letter (January 2023) from the Adult Principal Social Worker Network to the Secretary of State for Health and Social Care and the Minister of State for Social Care, which argued for the re-introduction of ward based social workers (Adult Principal Social Worker Network, 2023). Recent evidence has considered the role of ward based social workers and identified that there is a research gap in relation to the contribution and value of the social worker role in this environment (Heenan and Birrell, 2018). Further evidence is required that considers how the social worker role could support the wellbeing of people living with dementia and their carers during the hospital discharge. This role could potentially address many of the issues identified by carers in this analysis, including limited communication and signposting.

There was mixed evidence regarding the request by both carers and professionals to assess discharge options in the community (NHS Providers Community Network, 2022; Jeffery *et al.*, 2023). The discharge to assess model implemented during the pandemic was praised by participants but the potential for inappropriate discharges was also highlighted. Some academics have recently identified that the benefits of the discharge to assess model are not fully known (Jeffery *et al.*, 2023). The NHS Providers Community Network (2022) has argued that discharge to assess models are cost saving and enable hospitals to manage workloads more effectively. Ultimately, discharge to assess models are based on funding availability and extra research into the impact of this model on the wellbeing for people living with dementia and their carers is needed.

The next section of this chapter shall further consider the socio-political context of the discharge process and additional reasons why the focus of the process should be on supporting the wellbeing of people living with dementia and their carers.

11.8 The socio-political context of the discharge process and the requirement for a different approach.

Previous discussion within this chapter has revealed the requirement for a different approach to healthcare policy in relation to people living with dementia and their carers. It is arguable that a different approach could be achieved through a change in the political theory within the health and social care sector in the UK. The marketisation introduced into the NHS via the Health and Social Care Act (2012) was heavily criticised for its emphasis on competition rather than collaboration (The Kings Fund, 2012). The ongoing focus of austerity over the previous ten years has led to cuts in public services, local governments and NHS funded bodies which have striven to find ways of reducing their budgets (Stuckler *et al.*, 2017). Stuckler *et al.* (2017) has argued that austerity measures have had a significant negative impact on the most vulnerable in society in relation to health care accessibility. An issue that arose frequently in interviews was the complexity of the system for carers and the lack of clarity around funding options and finance, and how this prevented any emphasis on wellbeing within the process. Michael, Jack, Anne, Shelly, Elizabeth, and James all discussed at length the problems this caused for the people they cared for, and the cumulative impact on their own wellbeing.

A variety of the participants discussed the inaccessibility of support for carers and the patchiness of provision in care packages and admiral nurse availability. Some academics (McGregor, 2001; Schrecker, 2016) would argue that this is the outcome of pervasive neoliberal policies within the health care system (Becker, Hartwich and Haslam, 2021). Neoliberalism (Sakellariou and Rotarou, 2017) is largely defined as a political epistemology which emphasises the free market above the rights of individuals to health and social care. The impact of the neoliberal agenda has demanded de-centralisation of services and the invasion of market forces causing risk and responsibility to be laid on the individual (Mooney, 2012; Collins, McCartney and Garnham, 2016). Globally, this has led to inequities in access to healthcare and criticism that the most vulnerable are often severely disadvantaged (Sakellariou and Rotarou, 2017; Baru and Mohan, 2018) These themes were reflected in the data with carers feeling abandoned to manage risk around medication (Harriet) or struggling to organise and pay for equipment (Amy).

The data from this study supports the perspective that there is a pervasive neoliberal influence within the hospital discharge process. Carers often spoke about paying out of their own pocket for support or decrying the bureaucracy of systems that at the end of a long process, do not allow access to any financial support. This was experienced by both Jack and Anne. Academics have argued that the marketisation of healthcare is corrosive and ultimately devalues the worth of non-financial aspects of the discharge process, for example wellbeing, whilst simultaneously valuing the cost of services and treatments (Feiler, Hordern and Papanikitas, 2018). Therefore, it can be argued that the neoliberal agenda identified in the discharge process is having a negative impact on the wellbeing of individuals with dementia and their carers.

This argument is supported by wider academic research which has identified that the neo-liberal focus on the responsibility of the individual leads to high rates of anxiety and the internalisation of negative psychology (Sugarman, 2015). It is worth at this point identifying that a neo-liberal approach would not support the notion of wellbeing as a sound objective of the hospital discharge process. It would expect both the market and individuals to provide this independently. Neoliberal perspectives would not identify any responsibility on the part of the health and social care system, or the UK government, or collectivism towards supporting wellbeing (Pownall, 2013). If the experiences described by professionals and carers of limited community service availability, and a lack of clarity in relation to the discharge process are due to de-centralisation because of a neo-liberalist agenda, this must be addressed by a shift in policy away from marketized health and social care. Many academics and professionals have argued for this previously as the result of a neo- liberal health and social care system for people living with dementia and their carers is bleak (Mooney, 2012). The over emphasis on individualism can exert a terrible toll on carers and people living with dementia within the community and this is also true of the hospital discharge system (Ramon, 2008).

However, the UK still has a universal health care service and social care system (even if means tested) and it has been identified that there is the ability to improve on current practice and make choices that move away from de-centralisation and assigning responsibility to the individual and their carer (Adams *et al.*, 2019). There have been policy decisions made during the pandemic which move away from neo-liberal approaches. The introduction of furlough and the public health campaign which urged people to think as one integrated society, 'thank you NHS,' rather than acting in self-interest. This, alongside the decision to prioritise the needs of those classed as 'vulnerable,' reveals that the UK general population still have some ideals that would support the centralisation of wellbeing within the discharge process. It has also been shown that populations balk at the concept of neoliberal societies and prefer concepts of fairness and justice. This ensures that political policies, such as austerity measures, are not popular (Kashima, 2019).

Within the new Health and Care Act (Department of Health and Social Care, 2022a), there has been a marked shift away from de-centralisation and emphasis on market competition and towards collaboration via Integrated Care Boards. However, criticism from The Kings Fund (The King's Fund, 2021) has highlighted that the Act has significant limits and does not address the financial difficulties of the health and social care system, nor does it delineate how collaborative approaches between different bodies shall operate. The results of this study would indicate that a tonal shift towards wellbeing is required to re-focus policy to ensure that health and social care is focused on the needs of the individual and not the system. A movement away from neoliberal emphasis on competition in favour of collaborative approaches, would support a shift towards wellbeing being a central concern of the discharge process. In this section, I have considered how the recent change in the socio-political landscape away from neoliberal concerns may enable wellbeing to become centralised within the discharge process. In the next section, I will consider how COVID 19 impacted on the discharge process further and what lessons may be abstracted to aid any future pandemics.

11.9 The impact of COVID 19 and lessons to be learnt.

Objective 4: Identifying how guidance from ‘COVID 19 hospital discharge requirements’ impacted on the discharge process during the COVID 19 pandemic.

COVID 19 had a significant and penetrating influence on the discharge process. The ways in which COVID 19 affected the discharge process are presented within the findings chapters of this thesis. There is a requirement to learn from the pandemic and the conditions it created to improve the discharge process. The two most significant ways in which the discharge process was impacted by the

COVID 19 pandemic was evidence of a faster discharge process and the curtailing of visiting. These impacts shall now be discussed.

In chapter 3, I discussed the policy introduced during the pandemic in relation to the hospital discharge process at length. In this section, I will revisit the policy to identify how the empirical findings are related to the policy issued. The original guidance issued in section 1.3 of the COVID-19 Hospital Discharge Service Requirements (Department of Health and Social Care, 2020a) in March 2020 placed accountability on acute hospitals to discharge all patients home where possible. The discharge to assess model was introduced (section 1.8) which aimed to promote assessments being completed in the community following hospital discharge. The discharge lounge was established (section 2.2), which quickly moved patients away from the wards on which they had been cared for into transitionary wards once the decision to discharge was made. Clarity was delivered in relation to funding being available (section 2.8) to enable quicker discharges where social care was required. Therefore, priority was given to discharging people living with dementia as quickly as possible above all other concerns and considerations. The result of this was identified by carers and health and social care professionals within the empirical analysis of this study, namely, the creation of a discharge process that was occurring too quickly, with the correct assessments not being carried out.

The letter addressed to all Trusts on 17 March 2020 urged that alongside social distancing measures, visits to patients were to be curtailed with phone calls offered as a potential replacement. It is known that most hospital NHS Trusts stopped visiting or reduced visiting significantly during this period and the impact of this was discussed by carers at length within the data. The impact of an inability to visit was identified by a number of carers as having an extremely negative impact on the discharge process. Any agency or sense of control over actions for carers and people living with dementia was prevented due to the policy introduced during the pandemic.

A recent systematic review by Bailey *et al.* (2022) identified 14 papers outlining the experiences of informal carers during the pandemic period. Fear and uncertainty were identified as two of the themes across the published research. This direct correlation with the findings of this study reveals the importance of this analysis for presenting the impact of the pandemic in this context and for this carer dyad. The research published considering the wellbeing of people living with dementia and their carers during the pandemic by Hanna *et al.* (2022) and other academics (Lightfoot *et al.*, 2021; Maćkowiak *et al.*, 2021), has been community focused and identified problems for carers, such as loneliness and isolation in the community, and the inability to access community services (Sriram, Jenkinson and Peters, 2021). The findings presented in this thesis outline how these experiences in the community were echoed within the hospital discharge process. The available evidence from the review (Bailey *et al.*, 2022) does not include professional perspectives of the pandemic alongside carer narratives. This further highlights the unique nature of the analysis available in this research project and addresses the secondary aim to expand the evidence base available to clinicians and policy makers in this topic area.

A crucial lesson to be learnt from the impact of the COVID 19 pandemic guidance was the negative impact of the prioritisation of medical concerns above social concerns for patient wellbeing. Carer narratives revealed how distressing this was for the carer and person living with dementia, and how difficult it made arranging an adequate discharge. This experience was outlined by Jane, Katie, Jack, and Carol who all faced significant difficulties due to pandemic guidance and policy. The policy approach taken should not be repeated in future pandemics for people living with dementia. It is the contention of this thesis that relegating wellbeing and person-centred care as a secondary concern to infection control measures, is not appropriate for people living with dementia and their carers, within the hospital discharge process. The inappropriateness of the Government guidance during the pandemic for people living with dementia has been identified in Talbot and Briggs (2021), who advocated for more nuanced and accessible guidance. The findings of this research would support this nuanced approach in future pandemic contexts.

As previously mentioned in chapter 3, the Judgement delivered by the high court on April 27th, 2022, found the policy issued between 17th March and April 4th, 2020, unlawful, and guilty of failing vulnerable adults being discharged from hospital (Holt, 2022). This judgement vindicated the argument of this thesis, and its contention that future policy should focus specifically on ensuring the wellbeing of people living with dementia and their carers above other concerns including infection control. Emerging evidence supports this conclusion (Hughes, Liu and Baumbach, 2021; Wong *et al*., 2022; Hanna *et al*., 2022) with research showing that the emphasis on infection control measures outside of the hospital discharge process, led to negative outcomes for people living with dementia and their carers. However, some research has suggested that infection control measures may not always be a barrier to the wellbeing of adults living with dementia in the hospital context, if there is an awareness of the need for a balanced approach (Page, Davies-Abbott and Jones, 2021). Page, Davies-Abbott and Jones (2021) used the dementia care mapping method to identify that wellbeing on acute wards could still be high for people living with dementia, even during the pandemic with prolific use of PPE, if mental health nurses acted to modify the impact of pandemic regulations. This demonstrates that there is a requirement for significant flexibility in the infection control measures applied to people living with dementia and their carers that can prioritise wellbeing where necessary.

This section has demonstrated the importance of not relegating the wellbeing of individuals to secondary importance in pandemic contexts. In the final section of this chapter, I will reflect on the limitations of this research project, the further research required to advance the evidence base in this field and the implications of the research for policy makers, health and social care providers, integrated care boards, clinicians, and charitable bodies. Lastly, we will reflect on the importance of maintaining wellbeing for people living with dementia and their carers and the value of this research project.

11.10 The value of the Appreciative Inquiry process and the importance of the concept of wellbeing within the discharge process

The Appreciative Inquiry process (see chapter 4 for summary of the approach) was invaluable in revealing the insights and ideas of professionals and carers, in relation to wellbeing within the hospital discharge context (Whitney and Trosten-Bloom, 2010), and the factors that ensure wellbeing for this carer dyad. Engaging in the Appreciative Inquiry cycle (Cooperrider and Whitney, 2005) allowed the perspectives of carers and health and social care professionals to be central to these first stages of the potential change process, in accordance with social constructionist concepts of constructed entities (Cooperrider and Whitney, 2005).

Definition, discovery, dream, design, and destiny were incorporated into the method of the research project which aimed to ‘define’ wellbeing for carers and health and social care professionals, ‘discover’ the perspectives and experiences of this population of the hospital discharge process and ask them to ‘dream’ of improvements to the overall process (Bushe, 2011). The ‘design’ of the wellbeing framework was also facilitated. The final ‘delivery aspect’ of the Appreciative Inquiry cycle was not part of this research project. Understanding the insights of professionals into what they believe would improve the discharge process is vital to ensuring that any future implementation study, which would complete the ‘delivery’ aspect of the cycle, is feasible and would be supported by professionals.

The Appreciative Inquiry method allowed explicit consideration of the perspectives of health and social care professionals and carers, of the changes that would enable the discharge process to focus on wellbeing. In accordance with the Appreciative Inquiry method (Cooperrider and Whitney, 2005), the focus on evident strengths of the discharge process allowed this research project to focus on how wellbeing is, and could be, further supported in practice. This is in opposition to a problem-solving based approach which focuses on weaknesses within a process. Analysis of the ‘dream’ section of the carer data revealed that a move towards wellbeing would also be welcomed by this patient-carer group. Carers requested further respite, signposting, information about financial implications and explanation, and support to enable them to navigate the discharge process and this was discussed within the findings chapters.

The Appreciative Inquiry process used within this project was similar to the process outlined by Scerri, Innes and Scerri (2019). I asked participants to describe their positive experiences, and I highlighted these experiences in the findings section and to inform the framework. Scerri, Innes and Scerri (2019) developed ideal scenarios in workshops, I asked participants to detail what may have improved their experiences, and the outcomes of these discussions are detailed in the Dream section of the findings. Carers often had insight into the actions that would have improved the process and were detailed in their need for explanation, respite, being given choices, clarity regarding medication management and more specialist dementia nurses.

Michaels (2005) and Havens, Wood, and Leeman (2006) and Carter *et al* (2007), identified that focusing on successes can help further achievements, and help move towards positive improvements in a process. Further to this, Carter *et al* (2007) argued that the Discovery and Dream phases should take place simultaneously. This occurred within my research project across both interview sets, and I ensured the follow up of any positive stories within interviews. Professionals were asked to reflect on the best aspects of the process, alongside considering what could improve the process. Reed *et al* (2002) identified the importance of listening to both positive and negative stories, and similar to the work of Page (2020), this was facilitated during this project by asking generative questions (Gergen, 1982) from the topic guide such as- what support (emotional/physical/social/practical) did you receive during the discharge process from health and social care professionals? What went well during the discharge process? What support has helped you to maintain your physical and emotional well-being following your relative/friend’s hospital discharge?

Hammond (1998), Havens, Wood, and Leeman (2006) and Reed (2007) identify that it is important within the Appreciative Inquiry method to include all findings, and not gloss over negative findings, or ignore some findings in favour of more positive narratives. I also adhered to this tenet and included negative findings within both the findings chapter and in the framework. It is important to learn from both positive and negative narratives and Reed (2007) identifies that the flexibility of the Appreciative Inquiry method is one of its strengths in relation to form and function. I also found this, as the Appreciative Inquiry approach allowed me to utilise interviews to identify potential strengths of the discharge process, but also areas that require improvement without having to ascribe to a particular method. Further to this, different Appreciative Inquiry projects utilise different methods of development and progression of their findings and outcomes. While I developed a framework, other researchers as described in Trajkovski *et al* (2013) and Page (2020), have progressed their findings through workshops, focus groups or returned to an earlier phase of the Appreciative Inquiry cycle. Reed

(2007) identifies that the Appreciative Inquiry process is not linear and re-visiting earlier research phases can be a part of the research process. This flexibility entails that developing the findings from this project in future research can be adapted as required.

Carter (2006) identified that it is important that any Dream concepts are representative and achievable, and this can cause some problems within the Appreciative Inquiry method if participants have unrealistic expectations. However, I did not find this to be problematic with either group of participants who had lived experience of the processes of discharge, and reasonable insights into changes needed. This finding was also reflected in the work of Page (2020) who identified that the Appreciative Inquiry method can help professionals to glimpse potential changes to practice. Professionals often identified changes in paperwork or interprofessional working, which would be achievable. Similar to the findings of this project, Hammond (1998) identified that language usage is central to changing processes, and I also came to that conclusion within this project, particularly in relation to the term wellbeing.

Scerri, Innes and Scerri (2019) and Reed (2007) identified that Appreciative Inquiry has a potential strength in its specificity and context explicit focus. This was helpful during this project due to the impact of the pandemic and the way it impacted upon the discharge processes. The context specific nature of the Appreciative Inquiry process has allowed for the development of the framework and will allow specific focus on this context for this carer- patient dyad. Scerri, Innes and Scerri (2019) and Trajkovski et al (2013), identified the importance of key stakeholder buy- in within the cyclical process of the Appreciative Inquiry method. Shendell-Falik, Feinson and Mohr (2007) and Page (2020), utilised workshops and focus groups to develop the findings of their Appreciative Inquiry further. For this project, the development of the framework would benefit from following the methods of these previous projects and utilising workshops with stakeholder input. Page (2020) identified that the Appreciative Inquiry four phase process allowed the nurses in his study to change their understanding and attitudes towards people living with dementia. Although in my study participants were only interviewed once, it was evident that the reflection occurring during the conversations was allowing participants to move towards an understanding of the importance of tolerating some risk to support individual wellbeing.

The importance of higher level and management stakeholder input was identified by Turner *et al* (2017) and would be an important consideration for progressing the framework in future research outside of the scope of this thesis. Further to this, Carter, Cummings and Cooper (2007) identified the importance of developing timelines and achievable plans for implementing change. This would represent a valuable future project for the development of the findings of this project.

This section has considered the strengths and weaknesses of this research project. The Appreciative Inquiry approach has been identified as a significant strength, alongside the inclusion of both carer and professional insights. In the next section, I will identify the further research required in this area which has been revealed by this project’s findings, including the development of the wellbeing framework, research in conjunction with people living with dementia and the need for an ethnographic study.

Chapter 12. Conclusions of project

The primary aim of this research project was to explore the facets of wellbeing for adults living with dementia and their carers, during the discharge from hospital process, in both the pre and post COVID 19 contexts. A secondary aim of the research project included contributing to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing needs of this patient and carer group in the post COVID 19 climate.

The Appreciative Inquiry method has shown the need for change within the process, and specifically the requirement for wellbeing to be centralised within future hospital discharge practice. The framework developed from the findings of the project indicates that there is a requirement for the wellbeing needs of people living with dementia and their carers to be placed at the heart of the hospital discharge process.

The six areas of the framework outline the main areas which require change and further consideration within the discharge process. These are: for wellbeing to be a primary concern of the discharge process that moves beyond only physical pre-occupations; for there to be a tolerance of risk within discharge planning; the need for a clear road map available of the discharge process for the carer (transparent processes); for the carer and person living with dementia to be care partners with health and social care professionals; a need for the identification of adequate resources for carers and people living with dementia (accountability); and for the centralisation of the carer and person living with dementia, within the process, from admission to discharge.

Professionals within the discharge process must ensure that individuals living with dementia, and their carers, are able to maintain hope, personal worth and agency. This holistic approach can be achieved through a reconsideration of the process to prevent the dominance of the hospital concerns and preoccupations during hospital discharge.

In response to the primary aim of this research project, the facets of wellbeing during the discharge process include the ability for patient and carer to have agency, hope and personal worth during the discharge process and beyond. Agency is comprised of processes that ensure carer involvement, proactive individuals supporting empowerment and contexts that enable equality and risk taking. Hope is defined by moving beyond physical needs (actualisation) and a supportive environment (finance and services for carers). Personal worth is comprised of ensuring person-centred care and being treated as a care partner. These concepts have been developed in both the findings and discussion chapters of this thesis.

A secondary aim of the project was to further develop the evidence base available to policy makers, clinicians, and academics in this area. The impact of the pandemic, and pandemic policy, on the discharge process has also been outlined, and the requirement to balance infection control measures with wellbeing for this demographic in future comparable scenarios has been identified. Further definition of the concept of wellbeing and potential changes to the process have been outlined, contributing to the requirement to develop the evidence available further.

12.1 Limitations and strengths of the research project

As with any research project, there are several limitations that should be considered when interpreting the evidence presented. One of the earliest findings of the systematic review synthesis was that carers often undermine the viewpoint of the person living with dementia. Due to ethical constraints and the impact of social distancing due to the pandemic, I could not directly speak to individuals living with dementia about their wellbeing or the hospital discharge process. I believe that the opinion and perspective of people living with dementia should be sought on all topics and that further research is required to address this gap in the evidence available. Future work should look to focus on the perspectives, opinions, feeling and thoughts of people living with dementia singularly. There is a need for future ethnographic work in the hospital context with people living with dementia to understand their perspective of their own wellbeing and how that could be increased. Such a project would be feasible in the post- pandemic context where access to hospital spaces is no longer restricted.

The Health Foundation (2021) reported on some of the challenges faced by the NHS and the social care sector due to the pandemic. Staff shortages were caused by isolation requirements, health and social care professionals being ill with early variants of COVID 19, parents' inability to work due to schools being closed or other caring duties. It was challenging in this context to recruit many of the professional groups' integral to the discharge process.

The limited number of professionals interviewed for this research project reflects the lived reality that services were extremely stretched by the pandemic context. On one occasion, a physio therapist cancelled an interview three times due to the workload caused by colleague absences. The limited data collected is a limitation of this research project, however, due to the unique period in which this study was undertaken, and the unique data collected during this specific period, it is important to recognise the value of the data collected during these very pressured times.

It was also challenging to recruit spousal carers during the pandemic context due to the immense pressures that carers were under during this time. There was no respite available, no day centres and no legal way to mix with other families during the pandemic. Therefore, many interviews took place with carers and the person living with dementia present. Carers could not leave the person living with dementia and therefore, interviews were often interrupted by carers needing to attend to the needs of the person living with dementia.

I was unable to access any physical locations during this research project due to the impact of the pandemic. I was unable to implement an ethnographic study which I still believe is required to address the research gap in relation to wellbeing during this process. These restrictions caused by the pandemic context reflect another identified limitation. Interviews were carried out during England's lockdown in 2021 before the presence of a vaccine in any significant capacity, and later in the year as the country began to unlock in Summer 2021. Therefore, the interviews reflect the manner of the hospital discharge process during this period. It could be seen as a limitation that the data reflects this unique period. However, this limitation is in many ways a strength of the research project. The experiences of carers and health and social care professionals during the pandemic is captured in the data and is therefore, valuable in highlighting the perspectives and opinions of individuals during the COVID 19 pandemic.

This research project was a qualitative project carried out remotely during the pandemic. As a result, its wider applicability is limited outside of theoretical development. However, the aim to develop the evidence base in this area and the concept of wellbeing for people with dementia and their carers within the context of the hospital discharge process, is a worthy and valid endeavor. Due to the subjective and socially constructed nature of the concept of wellbeing, it is necessary that rich qualitative data is accessed that fleshes out this concept further. Due to the rising profile of the concept of wellbeing within health and social care policy and particularly in relation to the discharge process, further development of this concept and what it means to carers and professionals is essential. Identifying the factors that carers and professionals believe ensure wellbeing during this process is also important for advancing professional practice, policy, and indicating where further research is required.

Another limitation of the research project is the constraint to the consideration of wellbeing within the hospital discharge process only. As this undertaking represents a qualitative project focusing on the hospital discharge process during the COVID 19 pandemic, there is no capacity to focus broadly on the social care sector or domiciliary care in the community. These topics are valid research areas which require further exploration and consideration. There is an argument that wellbeing within the discharge process is simply part of a wider conversation about how carers and people living with dementia are treated. However, that discussion is for future and larger research projects to explore.

There were several strengths to this research project. One strength is the ability to access both carer and professional perspectives on this topic. Previous research has often focused on carer or professional perspectives without combining and comparing the data (Bauer, Fitzgerald and Koch, 2011; Bloomer *et al*, 2016). This research project has benefitted from being able to compare both perspectives to enable a more nuanced analysis of wellbeing in this context. The Appreciative Inquiry (Cooperrider and Fry, 2020) analysis enabled a focus on positive areas of the discharge process allowing the revelation of actions that support wellbeing. The Dream aspect of the Appreciative Inquiry method enabled a focus on the changes professionals and carers would advocate for within the discharge process, and this has enabled the beginnings of the development of a framework to include wellbeing as a central consideration during the discharge process.

12.2 Further research required.

Firstly, the framework included in this section requires significant further input from professionals and carers and people living with dementia. It requires development and refinement within the NHS setting. Its usage requires analysis by professionals and piloting of the framework in the post- pandemic period to fulfil the ‘design’ phase of the Appreciative Inquiry cycle. The specific actions required during the discharge process to implement the framework need further investigation in context. Such a project is beyond the scope of this thesis, but the development of this framework has revealed more about the nature of wellbeing for carers and people living with dementia during the discharge process, and the gaps in practice and availability of evidence.

This research project utilised the Appreciative Inquiry method to consider the changes professionals and carers believe would ensure the wellbeing of people living with dementia and their carers during the discharge process. However, the ‘Dream’ section of the Appreciative Inquiry cycle represents only the fourth section of the process. The wellbeing framework only the fifth section. This research project does not explore the next phases of the cycle which include building on the design phase, and moving into the destiny phase, where a product is co-designed and ultimately implemented and this needs to be addressed in future research.

There is a requirement for research that involves interviews and/or discussions with people living with dementia that considers their perspective of the discharge process, and methods of ensuring their wellbeing. It was not possible due to practical and ethical concerns of the pandemic period to include those living with dementia, but this is a priority for future research in this area. Based on the findings of the systematic review, there is no primary data that involves direct interviews with people with dementia. While this research represents a challenging endeavour, it would not be impossible for a researcher with the right skills and experience of the hospital setting, and interviewing people with dementia. Interviews with people living with dementia have been successfully undertaken previously (Samsi and Manthorpe, 2020). There is a significant research gap in relation to the perspectives of people living with dementia that undermines the evidence available and the acknowledgment of the personhood of individuals with dementia. It is right that their views and perspectives are sought to ensure a discharge process that reflects their needs and perspectives in relation to wellbeing.

The original aim of this research project, in a pre-COVID 19 context, was to undertake an ethnography of the discharge process located on a hospital ward. There is still a requirement for this ethnographic research as observational ward-based projects are few, and there is a need for ethnographic data to reveal what cannot be made visible in an interview medium. Ethnographic data would allow the perspective of people living with dementia, who may not have the ability to take part in an interview to contribute their thoughts and perspectives. An ethnographic study may reveal more about the nature of wellbeing for people living with dementia than this study was able. It was not possible to interview people living with dementia via digital methods, but it would be possible to visually record their discharge journey. The requirement for an ethnographic study is even more vital following the pandemic. Research prior to 2020 does not reflect the changes made to the discharge process due to the pressures wrought by COVID 19. Ethnographic research in the post-COVID 19 era is vital to providing a full visual representation of the discharge process which can aid policy makers and practitioners.

The integration of the findings from this study with the literature available suggested that there is a need for research into the impact of online forums, which are led by carers, focusing on the discharge process and the provision of emotional support. There is also a requirement for research into the admiral nurse role within the discharge process. The positive impact of the admiral nurse role within the discharge process was not identifiable within the literature, although it has been acknowledged elsewhere (Gamble and Dening, 2017; Carter *et al.*, 2018) but was highlighted by participants. Another area which requires further exploration is the specific financial impact of the discharge process on carers of people living with dementia. This is a topic not explored within the literature, but it was identified as a significant consideration by participants which requires further research attention. Furthermore, the necessity for further research into the value of a discharge co-ordinator and a successful format for hospital discharge meetings which provide adequate planning was highlighted within the findings.

The wellbeing framework points to the value of the development of a roadmap of the discharge process aimed at people living with dementia and their carers. How a road map of the discharge process would operate, and what it would consist of, requires extensive further research. A potential focus could involve a participatory action research approach, which would involve both health and social care professionals and carers, and position carers and people living with dementia at the centre of the process. In the next section I will consider the implications for policy makers, clinicians, integrated care boards, charitable bodies and health and social care providers.

12.3 Implications for policy makers, clinicians, integrated care boards, charitable bodies and health and social care providers

12.3.1 Implications for policy makers

This research project has revealed that there is a requirement for policy that focuses on a more sustainable financial and care availability context. Integrated care boards are tasked with providing localised health and social care provision. These bodies must ensure that there are services available that meet the needs of people living with dementia and their carers to enable adequate planning during the discharge process. Services must be available to support wellbeing for carers and people living with dementia in the community and adequate funding must sustain this. Further to this, the findings of this study also call for further integration between community and acute services particularly in relation to admiral nurses.

The analysis of policy documentation in Chapter 3, revealed that there is a need for more transparent and detailed policy guidance in relation to the discharge process and wellbeing, than is currently available and which is updated to reflect the post- pandemic context.

Further detail regarding discharge protocols and clarity regarding the support that should be offered to carers is required, with specific guidance available for people living with dementia. A re-assessment of the discharge to assess model in relation to this carer-dyad should be considered in the post- pandemic period.

12.3.2 Implications for individual NHS Trusts

The analysis of the empirical data collected as part of this study suggests that current policy is not detailed adequately and that further comprehensive policy documentation is necessary (Department of Health and Social Care, 2013; National Institute for Health and Care Excellence, 2015). In response to this, there is a requirement for local NHS Trusts to develop localised policy which responds to some of the gaps evident within the national policy, including the importance of justified risk taking to prioritise wellbeing (National Institute for Health and Care Excellence, 2015). Local NHS Trusts face a challenging proposition tasked with providing wellbeing support to people living with dementia and their carers during the discharge process, with limited clarity concerning how that support should manifest from national policy documentation, and the absence of any new significant funding to ensure this.

12.3.3 Implications for health and social care professionals

The implications of this research project for professionals include- a requirement to promote agency, personal worth and hope for people living with dementia and their carers during the discharge process. This is challenging in a context that is not primarily concerned with wellbeing and in the absence of transparency regarding how to achieve this. Professionals must enable justifiable risk taking that supports the agency of the person living with dementia. Adequate training that incorporates the requirement to avoid bias and stigma when facilitating the discharge process and encourages consideration of wellbeing would be a potential positive outcome based on the findings of this research project.

A potential aid to achieving this goal would be use of the framework to enable wellbeing to be supported during the discharge process outlined within Chapter 9. A re-assessment of the language used, and the emphasis of the discharge process should be considered to prioritise the person living with dementia and their carer. Professionals must also ensure adequate and robust safeguarding of individuals living with dementia and their carer when leaving the hospital. Strong professional accountability for safeguarding during the hospital process should be incorporated further into the process. A training programme such as depicted in the work of Elvish *et al.* (2014) may help facilitate the incorporation of greater emphasis on maintaining wellbeing during this process. Both findings from the empirical data in the findings chapters and the policy outlined in chapter 3 (National Institute for Health and Care Excellence, 2016), discussed the importance of adequate planning and communication, therefore, professionals must centralise discharge planning within their practice.

12.3.4 Implications for charitable bodies

The implications of this research project suggest that charitable bodies should aim to focus resources on providing guidance to carers of people living with dementia in relation to the financial landscape of discharge process. Many charities already offer some financial guidance with resources online and telephone advisory appointments (Alzheimer's Society, 2022). However, the findings of this research project suggest that a service or resource directly focused on the discharge process would be beneficial. Further availability of admiral nurses could be a focus of charitable bodies and signposting to local respite service and groups focused on wellbeing and social activities, including online.

12.3.5 Implications for education

The findings of this thesis have several implications for nursing, medical and allied health education. The importance of making the right decision for the person living with dementia and their carer, at discharge, is evident from the analysis. It has been identified that being confident in one’s ability to make the correct decision is vital to ensuring the right decision is reached (Hagbaghery, Salsali and Ahmadi, 2004). Therefore, increasing education provision in this area is central to ensuring confidence for nurses in their ability to make shared decisions that enable the autonomy of the person living with dementia, and their carer. As mentioned in Chapter 1, there is a need for adult nurses to receive education regarding care planning for people living with dementia and their carers, and in relation to service availability in the community. This should be delivered via a number of different methods including case studies; reflection; virtual scenarios and engaging with lived experts (Cariñanos-Ayala, Arrue and Zarandona, 2022), with the aim of supporting decision making which will sustain the wellbeing of people living with dementia and their carers.

The utility of decision-making aids in supporting clinicians to make the right decisions has been previously identified (Gillespie, 2010). The Situated Clinical Decision-Making framework (Gillespie and Peterson, 2009) posits that focusing on both the context and the requirements of the person being discharged from hospital is vital. Using a decision-making aid such as this may enable nurses and other clinicians to concentrate on supporting the wellbeing of the person living with dementia and their carer, rather than hospital discharge process requirements. Therefore, there is scope for aids, such as these, to feature in nurse and clinical professional education in relation to hospital discharge decision making that supports wellbeing primarily.

In contrast to the argument made above, there is some evidence to suggest that it is organisational and unit contextual factors which impact on, and influence decision making (Nibbelink and Brewer, 2008). The impact of education on decisions made in practice was found to be negligible in both a qualitative study and a systematic review (Thompson and Stapley, 2011; Doherty-King and Bowers, 2013). This would suggest that an educational focus on the discharge process may not impact on practice. However, in direct contrast to this, there is some evidence to show that targeted education specifically related to medication management can improve outcomes at discharge.

Manning *et al* (2007) demonstrated that the use of a medication communication tool at the point of discharge, could improve patient satisfaction with communication connected to medication. This tool includes a section on potential side effects and contraindications. Incorporation of such a tool into clinician education could allow it to be used to aid communication at discharge. Further to this, Cordasco *et al* (2009) demonstrated that a tool aimed at individuals with low literacy levels, or who have English as a second language, was also successful at improving communication at the point of discharge. Therefore, further focus on the incorporation of tools into clinician education may be beneficial.

Participants identified that creating and communicating a discharge plan for the day of discharge was vital. Scotten *et al* (2015) identified that standardising interprofessional communication during the discharge process was central to improving communication and led to higher patient satisfaction levels. Therefore, focusing on improving and clarifying interprofessional communication around the discharge process within the education system, may be an important consideration to improving discharge planning. Wong *et al* (2011) identified that improving the communication skills of clinicians is central to improving discharge outcomes. Therefore, it may be argued that further focus on the importance of communication strategies to support wellbeing, at the point of discharge, is needed within pre-registration courses.

Case based learning has shown to be effective at allowing students to develop the confidence to make the best decisions (Kaddoura, 2011). Developing cases for reflection (Lillyman and Bennett, 2012), focused on the experiences of people living with dementia and their carers and for use in the pre-registration setting, may allow students to develop insight into best practice decision making that is tolerant of risk, whilst developing knowledge, skill and compassion.

In contrast to focusing on the pre-registration environment, Graham, Gallagher and Bothe (2013) identified that the biggest barrier to effective discharge planning and communication is the limited availability of time in the workplace, not the presence or absence of effective education. An answer to this argument is for workplace-based learning, where highly skilled, experienced nurses can coach less experienced nurses in person centred discharge planning (Rahayu, Hartiti and Rofii, 2016). This is with the aim to enable the maintenance of hope, personal worth and agency for both the person living with dementia and their carer. Jantzen (2019) identified that mentor-guides are excellent for facilitating in-context learning. Therefore, the most appropriate form of education related to the findings of this project may be the development of the role of the clinical educator within the hospital setting. This professional role could focus on an inclusive discharge process aiming to support the wellbeing of people living with dementia and their carers. Clinical educators should focus on enabling nurses to promote the agency of people living with dementia and their carers; upholding the value of treating carers as care partners; ensuring person-centred care for people living with dementia and supporting holistic needs.

12.4 Final conclusion

Maintaining the wellbeing of people living with dementia and their carers is vital and acknowledged not only in policy documentation but also in law. Further research regarding how this is achieved in all contexts in required, particularly in the current financial and political climate (Department of Health and Social Care, 2022a; Department of Health and Social Care, 2022b; Department of Health and Social Care, 2022c), and the context of an increasing population of individuals living with dementia. This research project has aimed to develop the evidence base in this area by revealing a potential definition of wellbeing, and detailing the factors that maintain the wellbeing of both carers and people living with dementia during the hospital discharge process. It was evident from the data that proactive health and social care professionals, supportive contexts in relation to both finance and care availability, person- centred care, care that considers the needs of carers beyond just physical considerations and contexts that support risk taking are vital to ensuring wellbeing.

It is hoped that the findings of the research project may contribute to a renewed focus on wellbeing as a central concern within the discharge process. It was argued that small changes in emphasis and framing may enable a shift away from medicalised concerns, and towards more holistic concerns of wellbeing for the carer and person living with dementia. The importance of wellbeing for this patient and carer group cannot be overstated and must be prioritised by clinicians, commissioners, and policy makers. Small changes to language and positioning within the process that might improve wellbeing and the value of these changes should not be underestimated.

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Chapter 14. Appendices

List of items

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1 Protocol for study interviewing professionals

What are the factors that ensure the wellbeing of adults living with dementia and their carers during hospital discharge? A qualitative study focused on factors that health and social care professionals identify as integral, to ensuring the wellbeing of people living with dementia and their carers, during the discharge process.

Staff perspectives on the hospital discharge process for people living with dementia being discharged home.

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Rationale

Requirement for further research focused on the discharge process in hospital for people living with dementia and their carers.

It is evident that cognitive impairment amongst older adults is one of the key health challenges currently facing the NHS (Alzheimer’s Society, 2016) and over a quarter of hospital beds are occupied by adults with a dementia diagnosis (Alzheimer's Research UK, 2018). The many challenges surrounding living well with dementia impact upon: the NHS; social support services; the housing sector; the UK economy and personally upon individuals themselves. It is therefore, unsurprising that recent governments have focused Department of Health guidance around the challenges of living well with dementia and shaping services in both the acute and community sectors, to suit the needs of this vulnerable and growing demographic of UK society (Department of Health, 2015).

A report by Healthwatch England (2015), highlighted an ongoing concern amongst local community networks regarding the process of hospital discharge, particularly for people living with dementia and their carers. A report by the Alzheimer's Society (2016) into hospital care for people living with dementia, found that poor discharge planning led to both higher re-admission rates and higher levels of nursing or care home admissions following discharge. These outcomes are highly undesirable for patients, carers and the NHS and the report focused on the need for further improvement in the discharge process.

The ability of the discharge planning process to bridge the gap, between the care and support required in hospital and the care required in the community, has also been identified, highlighting the importance of this process in ensuring the wellbeing of people living with dementia and their carers (Bauer *et al*., 2009). Overall, previous studies have not elicited the opinions of healthcare professionals who are ideally placed to advise on ways to ensure the wellbeing of people living with dementia and their carers during the discharge process.

Study design and objectives.

2.1 Aim and Objectives

2.1.1 Aim

The project aims to identify the factors that healthcare professionals identify as integral, to ensuring the wellbeing of patients living with dementia and their carers, during the hospital discharge process (Newcastle upon Tyne Hospitals NHS Foundation Trust).

The research findings will contribute to the developing evidence base available to policy makers and clinical professionals, in relation to the wellbeing and support needs of this patient and carer group during the discharge process.

Objectives

- To explore the current discharge planning process for people living with dementia and how the needs of patients and carers are identified and addressed.

- To identify what factors work well, during the discharge process and what areas may require further improvement.

- To identify how guidance from 'Transition between inpatient hospital settings and community or care home settings for adults with social care needs' (National Institute for Care and Excellence, 2015) and 'Dementia: assessment, management and support for people living with dementia and their carers' (National Institute for Care and Excellence, 2018) has been incorporated into hospital discharge practice for adults living with dementia.

- To identify mechanisms to enable health and social care professionals to support people living with dementia and their carers during the hospital discharge process.

- To explore how the COVID-19 pandemic impacted on the hospital discharge process for people living with dementia discharged to their home address and their carers.

2.2 Study design

A qualitative design, which will explore the opinions and perspectives of health and social care professionals involved in the hospital discharge process for people living with dementia and their carers.

Interviews will explore the factors that healthcare professionals identify as integral, to ensuring the wellbeing of patients living with dementia and their carers, during the discharge process. Interview participants will be asked to identify what factors work well during the discharge process and what areas may require further improvement, to improve patient experience. Interviewees will also be asked about the factors that enable them to provide support for wellbeing to both patients and carers. The impact of COVID-19 on the hospital discharge process and the well-being of patients being discharged to their home address and their carers, will also be discussed.

2.3 Site

Interviews with specialist staff based within Newcastle Upon Tyne Hospitals NHS Foundation Trust and across England.

2.4 Participants

Potential health and social care professionals for inclusion:

- Discharge Nurses
- Care Co-ordinators
- Dementia Specialist nurses
- Admiral nurses
- Staff nurses
- Social Workers
- Medical professionals
- Occupational therapists
- Physiotherapists
- Healthcare assistants
- Pharmacists

2.5 Recruitment

Purposive and theoretical sampling methods will be utilised to recruit a sample of health and social care professionals with insight into the hospital discharge planning process. Potential participants will be approached via email and asked to take part in the study. Links are already established between the researchers and the Newcastle Upon Tyne Hospitals Foundation Trust, as a co-supervisor is the Nurse Consultant for Vulnerable Older Adults within the Trust. Many potential participants are already known to the researchers via their professional network.

Other participants from outside the Newcastle Upon Tyne Hospitals Foundation Trust will be contacted via email through Newcastle University researcher professional networks or via the Clinical Research Network. Emergent findings will guide subsequent recruitment. A sample of at least 10-25 participants will be recruited.

2.6 Consent

No participants will lack capacity. Potential participants will be fully informed of the scope of the study and detailed information sheets will be provided to participants. Participants will be given 48 hours at least to decide if they would like to take part and the researcher will ensure that participants are aware that their participation is voluntary and that they may withdraw from the study at any time.

If the participant is happy and willing to go ahead with the interview, the researcher will receive written consent, following a detailed consent discussion, before the interview commences. The researcher will email the consent form in advance and ask that it be completed and sent back in the post. This will be documented.

2.7 Data collection

Interviews will take place via the telephone, Newcastle University licenced Zoom, Teams or Starleaf. If Zoom is the preferred medium of the interviewee, a private meeting with a required code and waiting room will be created. Interviews shall be recorded via voice recorder or zoom record and shall be immediately transferred onto a secure server at Newcastle University. The remaining audio recording will be deleted from the portable audio recorder or zoom account. The consent sheet shall be locked in a secure drawer, only accessible to Laura Prato. Personal data will only be accessed on a secure Newcastle University computer and will be kept on a secure Newcastle University server only accessible to Laura Prato and Dr Clare Abley.

Potential Questions

Describe your role in the discharge process

Describe the discharge process for patients living with dementia and their carers (including the incorporation of guidance from ‘Transition between inpatient hospital settings and community or care home settings for adults with social care needs’ (National Institute for Care and Excellence, 2015) and ‘Dementia: assessment, management and support for people living with dementia and their carers’ (National Institute for Care and Excellence, 2018)

How are patient needs identified and addressed (including physical, psychological and social)? What factor help ensure that needs are met?

How are carer needs identified and met (including physical, psychological, social)? What factors help ensure that needs are met?

What would you identify as the best features of the current process?

What do you think could be improved?

How do you think the COVID-19 pandemic has impacted on the well-being of patients living with dementia and their carers during the hospital discharge process?

2.8 Data Analysis

Interviews and observations will be transcribed and analysed using thematic analysis. (Braun and Clarke, 2006). A coding framework will be developed, and themes will be analysed in depth. Qualitative data analysis software (NVIVO 11) will be utilised to manage and retrieve data.

2.9 Duration

Data collection and analysis shall continue for approximately 24 months commencing October 2020

Responsibilities and programme management

3.1 Sponsor:

Newcastle University.

3.2 Programme Management:

The Chief Investigator (CI) has overall responsibility for the delivery of this study. As the researcher (Ms Laura Prato) is a PhD student at Newcastle University, Dr Clare Abley will oversee the study as CI, due to her previous experience as a PI and NIHR Clinical Academic Training Lectureship holder.

3.3. PPI:

A patient and participant involvement group of carers for adults living with dementia have been integral in the design of this study. The researcher (Ms Laura Prato) has also consulted with a group of discharge nurses, nurse consultants, specialist dementia nurses, care-co-ordinators and social workers in the design of the study.

3.4 Research Governance:

Research Governance approval will be sought from the Newcastle Upon Tyne Hospitals NHS Foundation Trust and Caldicott approval shall be sought. The researcher (Ms Laura Prato) will be involved in data collection and will apply for a research passport, referring specifically to access for this study. The CI (Dr Clare Abley) has access to staff and patient data as part of her substantive contract as a nurse consultant employed by Newcastle Upon Tyne Hospitals NHS Foundation Trust. As the researcher (Ms Laura Prato) is a PhD student, insurance will be provided by the sponsor, Newcastle University. The CI (Dr Clare Abley) will be provided for, as part of her substantive contract of employment. Both researchers have completed Good Clinical Practice Training within the last three years.

3.5 Safety:

The safety of both researchers will be ensured by adhering to relevant Newcastle Upon Tyne Hospitals NHS Foundation Trust and Newcastle University policies.

2 Protocol for study interviewing carers

Ensuring well-being for people living with dementia and their carers following hospital discharge

A qualitative study exploring how to ensure the well-being of people living with dementia and their carers, during and after the hospital discharge process.

Protocol version 3
Date 13/01/2021
Funded by Economic and Social Research Council NINE DTP
Sponsored by: Newcastle University
IRAS: 287679

Rationale

Requirement for further research focused on the hospital discharge process and immediate period of return to the community for people living with dementia and their carers.

It is evident that cognitive impairment amongst older adults is one of the key health challenges currently facing the NHS (Alzheimer’s Society, 2016) and over a quarter of hospital beds are occupied by adults with a dementia diagnosis (Alzheimer's Research UK, 2018). The many challenges surrounding living well with dementia impact upon the NHS; social support services; the housing sector; the UK economy and personally upon individuals themselves. It is therefore, unsurprising that recent governments have focused Department of Health guidance around the challenges of living well with dementia and shaping services in both the acute and community sectors, to suit the needs of this vulnerable and growing demographic of UK society (Department of Health, 2015). The impact of the recent COVID 19 pandemic further intensifies the need for an abundance of appropriate and proportionate support mechanisms.

A report by Healthwatch England (2015), highlighted an ongoing concern amongst local community networks regarding the process of hospital discharge, particularly for people living with dementia and their carers. A report by the Alzheimer's Society (2016) into hospital care for patients with dementia, found that poor discharge planning led to both higher re-admission rates and higher levels of nursing or care home admissions following discharge. These outcomes are highly undesirable for patients, carers and the NHS and the report focused on the need for further improvement in the discharge process and the support available for carers and patients immediately following hospital discharge.

The ability of the discharge planning process to bridge the gap, between the care and support required in hospital and the care required in the community, has also been identified, highlighting the importance of this process in ensuring the well-being of people living with dementia and their carers (Bauer *et al*., 2009). The impact of COVID- 19 on the hospital discharge process and the immediate period of return into the community, for people living with dementia and their carers, is unknown. Further information relating to the process must be collected to ensure that people living with dementia and their carers are receiving the correct support during this pandemic and beyond.

Study design and objectives.

2.1 Aim and Objectives

2.1.1 Aim

The study will address the holistic well-being of people living with dementia and their carers during the discharge from hospital planning process and during the period of return to the community before, during and after the COVID- 19 pandemic. The project aims to identify the physical, social and emotional wellbeing (Department of Health, 2010) and support needs of carers and patients during and immediately after, the process of discharge, through a qualitative investigation of the hospital discharge process.

The research findings will contribute to the developing evidence base available to policy makers and clinical professionals, in relation to the well-being and support needs of this patient and carer group during the hospital discharge process and return to the community before, during and after the COVID-19 pandemic period.

Objectives

- To identify what support in relation to wellbeing (physical, emotional, social) carers and patients received during and after the hospital discharge process and whether this could be improved through a series of qualitative interviews.

- To identify support mechanisms and interventions which could be beneficial in promoting wellbeing during the discharge planning process and following discharge in the community through a series of qualitative interviews.

- To consider the potential barriers and facilitators to maintaining health and well-being during the leaving hospital process and in the community through a series of qualitative interviews.

2.2 Study design

A qualitative design, which will explore the opinions and perspectives of the carers of individuals living with dementia in relation to well-being for carers and individuals living with dementia during this hospital discharge process and on return to the community. The study will also explore the perspectives of volunteers in the community, who support people living with dementia and their carers.

Interviews with carers will explore whether patient and carer physical, social and emotional needs were addressed during the discharge process and what factors support well-being on return to the community. Alongside this, interviews will aim to identify support systems that would be beneficial in promoting well-being, during the discharge planning process and following discharge into the community.

Questions will explore- what support carers and patients have received during the hospital discharge process and whether this could be improved; whether carers have been adequately involved in and prepared emotionally and practically for their relatives discharge; an examination of existing community support networks and a consideration of the potential opportunities and challenges to maintaining physical health and well-being during and post-discharge.

Potential interview questions include:

What support (emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What could have been improved or helped you to feel more supported?

Did you feel adequately involved in the discharge process?

Did you feel prepared emotionally and practically for the discharge of your relative/friend?

What support do you have available to you in the community?

What support has helped you to maintain your physical and emotional well-being following your relative/friend's hospital discharge?

Has anything acted as a barrier to you maintaining your physical and emotional well-being following your relative's discharge?

How do you think COVID-19 has impacted on your experience?

What does well-being mean to you?

Interviews with volunteers will explore what support is available for carers of people living with dementia and the individuals themselves, following discharge from hospital into the community.

Potential questions:

- How do you/your organisation support the well-being of carers and individuals living with dementia after hospital discharge?

- What do you think are the main challenges to supporting well-being in the community immediately following hospital discharge?
- How do you think COVID 19 has impacted on the well-being of carers and individuals living with dementia during the hospital discharge process and following discharge into the community?

2.3 Site

Interviews with carers of people living with dementia and volunteers will be across the UK.

2.4 Participants

Inclusion criteria carers

Carers of people living with dementia who have been discharged from hospital in the last 3 years.

Carers who are related or unrelated to the person living with dementia and currently providing care for the person living with dementia (no set time period required).

Carers will be self-identifying, and the definition of carer will include all aspects of the caring role including physical, emotional, social, and organisational caregiving.

Carers must be over the age of 18 as the focus of the study is not on the role and experience of young carers.

Carers must be based in the UK.

Exclusion criteria carers

A carer under the age of 18

Relatives, friends, and family members who are not involved in the carer role.

Individuals who lack capacity (under the Mental Capacity Act (2005) and are unable to give informed consent.

Inclusion criteria volunteers

Volunteers who support people living with dementia and their carers in the community.

There is no set period that an individual has to have been a volunteer to qualify for inclusion in the study.

Volunteers must be based in the UK.

Exclusion criteria volunteers

Domiciliary care workers who are not in a voluntary role (this does not exclude individuals receiving carers allowance)

Individuals who lack capacity (under the Mental Capacity Act (2005) and are unable to give informed consent.

Individuals who live or provide care outside the UK.

2.5 Recruitment

Carers and volunteers will be recruited via social media and voluntary organisation mailing lists. Examples of these organisations include the Newcastle Elders Council and Dementia Matters. A sample of at least 20 carers will be recruited and 10 volunteers.

2.6 Consent

No participants will lack capacity. Potential participants will be fully informed of the scope of the study and detailed information sheets will be provided to participants via email or the post.

Participants will be given 48 hours at least after receiving the information sheets to decide if they would like to take part in the consent discussion. Laura Prato will ensure that participants are aware that their participation is voluntary and that they may withdraw from the study at any time.

Laura Prato will organise a detailed consent discussion (ensuring that the participant understands the scope, format and demands of the research) with the potential participant via phone, Teams or Zoom in advance of the interview. The confidentiality protocol will also be supplied to the potential participant to ensure they are aware of the occasions and circumstances where confidentiality may be broken.

At the end of the consent discussion, Laura Prato will receive informed consent, if the participant decides to take part in the research study and sign the consent form either electronically or via traditional wet signature. Laura Prato will wait until the consent form is emailed or sent via the post and will sign the form herself. After this has occurred, Laura Prato will arrange a date and time for the interview to take place.

Before the interview commences, Laura Prato will verbally check that the participant still wishes to take part in the research. This will be checked again at the end of the interview. If at any point the participant seems unhappy to continue the interview or is distressed during the interview, Laura Prato will again check that the participant is happy to answer the interview questions. This will be documented. At the end of the interview, Laura Prato will offer a wellbeing resource sheet to the participant if they request one and signpost them to their GP if this is necessary.

2.7 Data collection

Interviews will take place via the telephone, zoom or teams. Interviews shall be recorded via audio or video and shall be transferred onto a secure server at Newcastle University. The remaining audio recording will be deleted from the portable audio recorder. The recording will be deleted 3 months after the end of the study (approximately February 2023). The consent sheet shall be locked in a secure drawer on secure premises, which is only accessible to the researcher. Once practicable the consent form shall be transferred to Newcastle University premises. If the consent form is signed digitally, it will be stored on secure university systems. Personal data will only be accessed via a secure Newcastle University server only accessible to Laura Prato.

2.8 Data Analysis

Interviews will be transcribed and analysed using thematic analysis. (Braun and Clarke, 2006). A coding framework will be developed, and themes will be analysed in depth. Qualitative data analysis software (NVIVO 11) will be utilised to manage and retrieve data.

2.9 Duration

Data collection and analysis shall continue for approximately 24 months commencing December 2020

Responsibilities and programme management

3.1 Sponsor

Newcastle University.

3.3. PPI

A patient and participant involvement group of carers for people with a dementia diagnosis have been integral in the design of this study. The researcher (Ms Laura Prato) has also consulted with a group of discharge nurses, nurse consultants, specialist dementia nurses, care-co-ordinators and social workers in the design of the study.

3.4 Research Governance

As the researcher (Ms Laura Prato) is a PhD student, university professional liability insurance will ensure indemnity alongside indemnity provided by the sponsor. The CI and PI (Dr Clare Abley) will be provided for, as part of her substantive contract of employment. Both researchers have completed Good Clinical Practice Training within the last three years.

3.5 Data Management and GDPR

The researcher will follow the Data Protection Act 2018 and GDPR principles and ensure the anonymisation of all data. Participants will be issued a unique identifying number and personal information will be kept on one electronic document via Newcastle universities secure server only.

Personal information will be deleted at the end of the study.

Anonymised data will be kept on secure servers at Newcastle University. At the conclusion of the the research study, the data provided will be de-identified and made available as "open data" through a research data repository once the study has concluded [https://www.ukdataservice.ac.uk/deposit-data.aspx). This means the de-identified study data will be publicly available and may be used for purposes not related to this study. The data will be available indefinitely. It will not be possible to identify participants from the "open data".

3.5 Confidentiality Protocol and Distress Protocol

During the interview process, the researcher will utilise the confidentiality and distress protocol to protect both participant and the researcher wellbeing. The steps outlined in the confidentiality protocol will guide Laura Prato in situations where breaking confidentiality is required to safeguard participants, the researcher, and other vulnerable adults. The actions to be taken in the event of the requirement to break confidentiality are included below in section 4. The distress protocol to be followed during the interview is included in section 5.

4 Confidentiality Protocol

4.1 Requirement to break confidentiality following an interview.

4.1.1 General points

Laura Prato will discuss the potential need to break confidentiality in accordance with the confidentiality protocol, as part of the consent discussion.

If an immediate threat of harm emerges during the consent discussion or the interview, Laura Prato will alert the relevant authority/emergency service (Police/Ambulance). If the threat is not immediate, Laura Prato will advise and encourage the participant to contact the relevant authority/service.

If a safeguarding issue arises, Laura Prato will follow local policy and procedures for safeguarding vulnerable adults. She will also inform the PI (Clare Abley) and the study sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University.

If Laura Prato requires support, in relation to her own wellbeing outside of the supervision team, this is available via the mental health and wellbeing team based at Newcastle University.

4.1.2 Specific Actions

The following specific actions will be taken if necessary:

1) Participant says something that indicates suicidal thoughts e.g. ‘life so bad it’s not worth living’

Laura Prato will follow recommendations from the Samaritans and allow the participant to talk about their thoughts, determining whether immediate assistance or support is required.

https://www.samaritans.org/how-we-can-help/if-youre-worried-about-someone-else/supporting-someone-suicidal-thoughts/

If immediate support is required Laura Prato will ring the emergency services and request an ambulance, staying with the individual and providing support until the ambulance arrives. The study PI, Dr Clare Abley will be informed. The incident will be reported to the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University.

If immediate intervention is not considered necessary, Laura Prato will signpost the participant to their GP and / or other community support services e.g. Alzheimer’s Society, Mind. Laura Prato will contact the participant the day after the interview (if the participant consents to this) to offer further support. Laura Prato will discuss the incident with the PI, including any further action required.

2) Refusal of participant to inform the police of illegal activity.

If a participant discloses illegal activities and following advice from Laura Prato, refuses to inform the police, Laura Prato will contact the police. Laura Prato will inform Dr Clare Abley, the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University, of this incident.

3) Disclosure of adult abuse by a carer/relative/volunteer.

Adult abuse can take a wide range of forms (physical abuse; domestic violence/abuse; sexual abuse; psychological/emotional abuse; financial/material abuse; modern slavery; discriminatory abuse; organisational/institutional abuse; neglect or acts of omission; self-neglect). If adult abuse is disclosed during an interview, Laura Prato will follow local safeguarding policy and procedures and make a safeguarding referral. The PI and the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research at Newcastle University, will be informed.

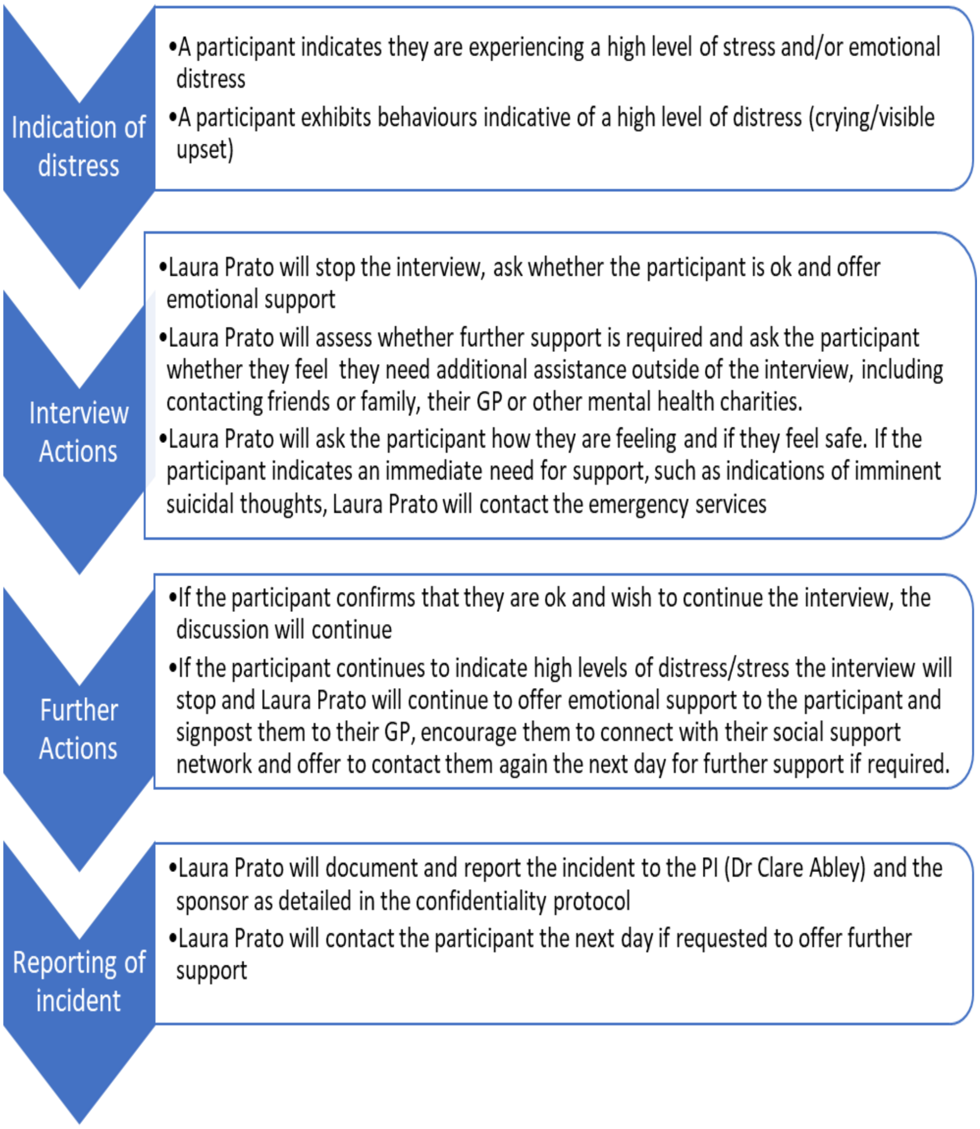
Laura Prato will contact Dr Clare Abley in the first instance if uncertain whether confidentiality should be broken. If required, further advice will be sought from the wider supervision team, which includes Professor Thomas Scharf, Professor Yvonne Birks and Dr Joy Adamson, and from the sponsor representative Kay Howes and Professor Andrew Blamire, the Dean of Translational and Clinical Research, at Newcastle University.

5 Distress Protocol

(Draucker, Martsolf & Poole, 2009)

Adapted from Draucker, Martsolf & Poole (2009) available at https://www.mmu.ac.uk/media/mmuacuk/content/documents/rke/Advisory-Distress-Protocol.pdf.

If during an interview, Laura Prato identifies that the participant is experiencing severe distress, she will follow the steps outlined in the diagram below:



Indication of distress

- A participant indicates they are experiencing a high level of stress and/or emotional distress
- A participant exhibits behaviours indicative of a high level of distress (crying/visible upset)

Interview Actions

- Laura Prato will stop the interview, ask whether the participant is ok and offer emotional support
- Laura Prato will assess whether further support is required and ask the participant whether they feel they need additional assistance outside of the interview, including contacting friends or family, their GP or other mental health charities.
- Laura Prato will ask the participant how they are feeling and if they feel safe. If the participant indicates an immediate need for support, such as indications of imminent suicidal thoughts, Laura Prato will contact the emergency services

Further Actions

- If the participant confirms that they are ok and wish to continue the interview, the discussion will continue
- If the participant continues to indicate high levels of distress/stress the interview will stop and Laura Prato will continue to offer emotional support to the participant and signpost them to their GP, encourage them to connect with their social support network and offer to contact them again the next day for further support if required.

Reporting of incident

- Laura Prato will document and report the incident to the PI (Dr Clare Abley) and the sponsor as detailed in the confidentiality protocol
- Laura Prato will contact the participant the next day if requested to offer further support

3 Participant information sheet carers

Staff perspectives on the hospital discharge process for patients living with dementia being discharged home.

Participant Information Sheet

You are invited to take part in an important research study taking place within the Newcastle Upon Tyne Hospitals NHS Foundation Trust. Before you decide we would like you to understand why the research is being done and what it would involve for you. Part 1 tells you the purpose of this study and what will happen to you if you take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1. Purpose of the study and what taking part involves.

This study is investigating the hospital discharge process for older patients living with dementia within Newcastle Hospitals Trust inpatient services.

A significant proportion of older people who are admitted to general hospitals and subsequently discharged will have problems with memory and cognition. In spite of this, little research has been done to explore their experiences or their carers' experiences, during the discharge process. Additionally, we know very little of the staff perspectives on the hospital discharge planning process for patients living with dementia and their carers.

This study seeks to gain a fuller understanding of the staff perspective on:

- Current practice of the discharge process for patients living with dementia who are being discharged home.
- How the needs of these patients and their carers are identified and addressed.
- How the COVID-19 pandemic has impacted upon the hospital discharge process and patient and carer well-being.
- How practice might be improved.

This information will be used to help improve the discharge process for future patients living with dementia and their relatives.

How can you be involved?

We appreciate that clinical staff have many demands on their time; however, we very much hope you will see the value in sharing your practice and experiences with us. For this research Laura Prato (ESRC funded PhD research student and RGN) would like to conduct research interviews with health and social care staff, involved in the provision of care to older inpatients living with dementia and their relatives during the hospital discharge process. Interviews will last no longer than one hour and will be held at a time that is most convenient to you. Interviews will take place either over the phone, starleaf, teams or zoom. We will seek your permission to audio record the interview or video record over zoom. The transcript of this interview will be fully anonymised, so that you cannot be identified.

It is entirely up to you to decide whether or not to take part in any aspect of this study.

What are the possible benefits of taking part?

Taking part in this study will give you the opportunity to express your opinions about the hospital discharge process for older adults living with dementia. You will also be able to share your experiences of caring for these patients and their carers / relatives, with an interested researcher. The material gathered for this study will generate an evidence base that can be used to positively shape future hospital discharge procedures for older people living with dementia.

What are the possible disadvantages of taking part?

The researcher, Laura Prato, will make every effort to be respectful during the interview. If you do not wish to take part in the interview or answer a particular question, you are free to leave at any time.

What if I don’t want to carry on with the study?

You are free to withdraw from the study at any time, without giving a reason. This will not affect your work life in anyway.

What if the researchers come across bad practice or harm to individuals?

In the unlikely event that any disclosures of bad practice or harm to individuals become apparent during the study, we will follow Trust Safeguarding Policies and Procedures.

Part 2. Further study information

What will happen to the results of the study?

This study will identify a wide range of staff perspectives on the hospital discharge process for older patients living with dementia. Summaries of the research findings will be published in academic journals; professional publications relating to Nursing and Social Care and, where appropriate local newsletters. All data will be anonymised, so that participants cannot be identified in any outputs from the research.

Anonymised data and identifying data will be kept on secure servers at Newcastle University and will not be accessible to anyone other than Laura Prato and her supervisory team. The study and data may be audited by Newcastle Upon Tyne Hospitals NHS Foundation Trust. Identifying data will be destroyed at the end of the study. Anonymised data will be destroyed in 5 years' time.

Who is doing the research and in what capacity?

The Chief Investigator for this project, Dr Clare Abley, is a Nurse Consultant for Vulnerable Older Adults employed by The Newcastle upon Tyne Hospitals NHS Foundation Trust. Since 2011, her work has focused upon improving acute hospital care for older people experiencing problems with memory and thinking.

Laura Prato is a Nurse and PhD student at Newcastle University. Her previous projects have focused upon the hospital experience of older adults with problems with memory and thinking.

Laura will be supported through the research according to Newcastle University processes including a thesis advisory team and will have additional supervision from Professor Joy Adamson (a methodologist in health research) Professor Thomas Scharf (a specialist in qualitative research) and Professor Yvonne Birks (providing expertise in health and social care).

Funding and ethical review

This project is funded by the Economic and Social Research Council. The study has been approved by the Newcastle University Ethics Committee, the NHS Health Research Authority and R&D at Newcastle Upon Tyne Hospitals NHS Foundation Trust.

Getting in touch

If you have any questions about the research either now or later, please contact:

- Laura Prato (email:

If you wish to complain formally, you can do this through the NHS Complaints Procedure. Details of how to complain can be obtained from the hospital.

General Data Protection Regulations

We will need to use information from you for this research project.

This information will include your name, email address and job title. People will use this information to do the research or to check your records to make sure that the research is being done properly.

People who do not need to know who you are will not be able to see your name or contact details. Your data will have a code number instead.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have.

Where can you find out more about how your information is used?

You can find out more about how we use your information

at www.hra.nhs.uk/information-about-patients/

or by asking one of the research team (Ms Laura Prato)

or by sending an email to (Data Protection Officer for Newcastle University)

4 Participant information sheet professionals

Ensuring wellbeing for people living with dementia and their carers following hospital discharge.

You are invited to take part in a research study on the well-being of people living with dementia and their carers when returning home from hospital. Before you decide whether you wish to take part we would like you to understand why the research is being done and what it would involve for you. Part 1 tells you the purpose of this study and what it will involve if you decide to take part. Part 2 gives you more detailed information about the conduct of the study.

Part 1. Purpose of the study and what taking part involves.

This study is investigating what happens when people living with dementia return home from hospital and what support is available within the community.

Many older people who are admitted to general hospitals and then discharged have problems with memory and cognition. Despite this, little research has been done to explore their and their carers' experiences after returning home from hospital. The impact of COVID-19 measures on the hospital discharge process and on the support available in the community is unknown.

This study seeks to gain a fuller understanding of:

- The community support available for people living with dementia and their carers.
- Opportunities and challenges to supporting wellbeing in the community immediately following hospital discharge.
- How COVID-19 has impacted on the hospital discharge process and available community support.

The information collected in this study will be used to help identify how the discharge process can be improved for people living with dementia and their carers. It will also be used to identify potential support mechanisms available within the community.

How can you be involved?

For this research, Laura Prato (an ESRC-funded PhD research student) would like to interview carers or relatives of people living with dementia in the community about their experiences of the hospital discharge process. Laura is also interested in your views on the discharge experience of the person you care for/your relative and your opinions on the support available in the community following hospital discharge.

Laura Prato is specifically seeking individuals over the age of 18 who would self-identify as a carer in any capacity including but not limited to emotional, social, physical, and organisational care. This does not include paid domiciliary care workers but does include individuals receiving carers allowance.

Interviews will last no longer than one hour and will be held at a time that is most convenient to you. Interviews will take place via telephone or Zoom or Teams. An informed consent discussion will take place before the interview on a separate occasion. This will be arranged for a time and date of your convenience. During this discussion we will talk about what taking part in the study entails, the potential benefits and disadvantages of taking part and the questions that will be asked. We will also discuss your right to not answer any questions or withdraw from the study at a later date. Further, we will discuss the confidentiality protocol and occasions when confidentiality may be broken.

If at the end of the discussion you wish to go ahead with the interview, the consent form will be signed and returned to Laura Prato electronically or via the mail. Once Laura Prato has received the consent form, a date and time for the interview will be finalised. The interview will not take place until Laura Prato has received the consent form. Before the interview, Laura Prato will ask you to confirm that you still give consent to take part in the interview and will ask again at the end of the interview. If at any point during the interview you become distressed, Laura Prato will ask whether you wish to continue. You may stop the interview at any time. We will seek your permission to audio or video record the interview. Recordings will be deleted 3 months after the end of the study (approximately February 2023). Interview transcripts will be anonymised, so that you cannot be identified. Recordings will not be anonymised but will only be accessible to Laura Prato or the supervisory team.

If you wish, a summary of the interview transcript will be sent to you following the interview.

It is entirely up to you to decide whether you wish to take part in this study.

What are the possible benefits of taking part?

Taking part in this study will give you the opportunity to express your views about the support available during the hospital discharge process and in the community for people living with dementia and their carers. You will also be able to share your experiences of being a carer/relative at this time, with interested researchers. The material gathered for this study will contribute to evidence surrounding improving hospital discharge procedures and community support mechanisms, for people living with dementia and their carers.

What are the possible disadvantages of taking part?

It is possible that you may feel distress during or after the interview. You may also find the interview inconvenient.

The researcher, Laura Prato, will respect your wishes during the interview and try to limit any distress caused by taking part. You should only answer questions or discuss topics that you wish to. If you do not wish to take part in the interview or answer a particular question, you are free to end the interview at any time. Laura Prato will provide you with a resource sheet of organisations that can provide wellbeing support following the interview if you wish.

Laura Prato will arrange the interview and consent discussion for times that are convenient for yourself.

What if I don’t want to carry on with the study?

You are free to withdraw from the study at any time without giving a reason until 6 months after the interview.

Will my personal information remain confidential?

Please note that your personal details (email/address/phone number) will always be kept confidential and will only be known by the researcher (Laura Prato). The data you provide during the interview will be anonymised and you will not be identifiable, nor will any person or place you discuss during the interview.

What if the researcher identifies malpractice or harm to individuals?

Please be aware that the researcher (Laura Prato) has a duty of care to disclose personal information to the relevant authorities (Police or other emergency services) if during the course of the interview she becomes aware of a risk of harm to yourself or someone close to you.

If you disclose an intention or knowledge of harm to yourself or others, the researcher has a moral, and potentially legal obligation to break confidentiality to protect you or others and to inform Dr Clare Abley as the Chief investigator.

This would also be the case if you disclose information regarding participation in illegal activities.

Also, if during an interview there is an immediate risk of self-harm, Laura Prato will ring an ambulance to safeguard your wellbeing.

If during an interview you indicate feelings of depression, Laura Prato will signpost you to your GP, support network and other support services offered by community groups such as Alzheimer's UK and/or Mind. Laura Prato will seek your permission to contact you the day following the interview to offer further support.

If you disclose illegal activities during an interview, Laura Prato will inform the police.

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If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral.

Part 2. Further study information

What will happen to the results of the study?

Summaries of the research findings will be published in academic journals, professional publications and, where appropriate, local newsletters. All information collected will be anonymised, so that participants cannot be identified in any outputs from the research.

Anonymised data will be kept on secure servers at Newcastle University and will not be accessible to anyone other than Laura Prato and her supervisory team until the end of the study.

If you agree to take part in the research study the data provided will be de-identified and made available as "open data" through a research data repository once the study has concluded [https://www.ukdataservice.ac.uk/deposit-data.aspx). This means the de-identified study data will be publicly available and may be used for purposes not related to this study. The data will be available indefinitely. It will not be possible to identify you from the "open data".

Who is doing the study and in what capacity?

This research is being undertaken by Laura Prato who is a nurse and PhD student at Newcastle University. Her previous projects have focused on the hospital experience of older patients with memory and thinking problems.

Laura will be supported by her PhD supervisory team:

- Professor Thomas Scharf Professor of Social Gerontology, Newcastle University
- Professor Joy Adamson, University of York
- Professor Yvonne Birks, University of York

- Dr Clare Abley, Nurse Consultant for Vulnerable Older Adults at The Newcastle upon Tyne Hospitals NHS Foundation Trust and Honorary Clinical Senior Lecturer Newcastle University

The chief investigator for this project is Dr Clare Abley.

Funding and ethical review

This PhD is funded by the Economic and Social Research Council. The study has been approved by relevant ethics committees.

Getting in touch and complaints

If you have any questions about the research either now or later, please contact:

-

If you have any complaints, concerns or comments about the research, please email: to discuss your concerns.

General Data Protection Regulations

Newcastle University will be using information from you in order to undertake this research study and will act as the data controller for this study. This means that Newcastle University is responsible for looking after your information and using it properly. When we use personally-identifiable information from people who have agreed to take part in research, we ensure that it is in the public interest. Your rights to access, change or move your information are limited, as Newcastle University needs to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study after 6 months, Newcastle University will keep the information about you that has already been obtained. To safeguard your rights, the minimum personally-identifiable information will be used. You can find out more about how Newcastle University uses your information at https://www.ncl.ac.uk/data.protection/dataprotectionpolicy/privacy notice/ and/or by contacting Newcastle University's Data Protection Officer.

We will use your name and contact details [telephone number, email and address] to contact you about the research study. Individuals at Newcastle University may look at your research data to check the accuracy of the research study. The only individuals at Newcastle University who will have access to information that identifies you will be individuals who need to contact you [Ms Laura Prato or Dr Clare Abley] or audit the data collection process.

If you agree to take part in the research study, information provided by you may be shared with researchers running other research studies at Newcastle University and in other organisations. These organisations may be universities or NHS organisations. Your information will only be used by organisations and researchers to conduct research.

This information will not identify you and will not be combined with other information in a way that could identify you. The information will only be used for the purpose of research and cannot be used to contact you. It will not be used to make decisions about future services available to you.

5 Topic guide carer interviews

TOPIC GUIDE

- Could you just describe a little bit your overall experience of your wife/husband/mum/dad leaving hospital?
    - What support (Emotional/physical/social/practical) did you receive during the discharge process, from health and social care professionals? What could have been improved or helped you to feel more supported?
    - Did you feel adequately involved in the discharge process?
    - What went well during the discharge process?
    - What could have gone better?
    - Did you feel prepared emotionally and practically for the discharge of your relative/friend?
    - What support do you have available to you in the community?
    - What support has helped you to maintain your physical and emotional well-being following your relative/friend's hospital discharge?
    - Has anything acted as a barrier to you maintaining your physical and emotional well-being following your relative's discharge?
    - How do you think COVID-19 has impacted on your experience?
    - What does well-being mean to you?

6 Consent form carers

CONSENT FORM FOR CARERS / RELATIVES

Ensuring wellbeing for people living with dementia and their carers following hospital discharge

I……………………………………………………………………. **(name)**

Please initial each

I have read the information sheet (version 3) dated 18/12/2020 giving details of this study, have been given a copy to keep and have had the opportunity to ask questions of the researcher. ☐

I understand that my participation is voluntary, and I can withdraw consent at any time, without giving any reason up until 6 months after my interview. ☐

I understand that this consent form and the data collected during the study may be looked at by individuals regulatory or ethical authorities, where it is relevant to my taking part in research. ☐

I give permission for information about me to be held by Newcastle University. I understand that records will be confidential and will be stored securely on systems within the University. ☐

I understand that interviews will take place via zoom, teams or telephone and I give permission for a video ☐

recording or an audio recording to be taken. I understand that only Ms Laura Prato and the supervisory team will view the video or listen to the audio of the interview.

I understand that anonymous extracts from the interviews may be used in disseminating the project findings. ☐

I understand that if I tell you something that suggests that someone is at risk, or illegal activities are taking place, you will inform the appropriate authorities as detailed within the confidentiality protocol. You will alert the Chief investigator (Dr Clare Abley) and the Sponsor (Newcastle University) of the confidentiality breach. ☐

If I indicate intentions of immediate self-harm, I understand that Laura will ring an ambulance to safeguard my wellbeing. ☐

If during an interview I indicate feelings of depression, Laura Prato will contact me the day after the interview to offer further support. ☐

If I disclose illegal activities during an interview, Laura Prato will inform the police. ☐

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If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral. ☐

I would/would not like a typed summary of the interview sent to me. ☐

I understand and give permission/do not give permission for researchers in the future to access the anonymous data provided for further research purposes. ☐

I understand and agree for anonymised data to be made available as “open data” through a research data repository once the study has concluded. ☐

☐

I consent to take part in this study and I understand that it entails voluntary interviews with the researcher Ms Laura Prato.

Signed.. ………
Date...............................

Print name..

Consented by …………………............... (signed)
Date...............................

Print name

....

7 Consent form professional participants

Staff perspectives on the hospital discharge process for patients living with dementia being discharged home.

I
(name)

of……………………………………………………………………………………………… **(Staff Role)**

I have read the information sheet which outlines the details of this study, have been given a copy to keep and have had the opportunity to ask questions. ☐

I understand that my participation is voluntary and I can withdraw consent at any time without giving any reason and without my legal rights being affected. ☐

I understand that this consent form and any data collected during the study may be looked at by individuals from the research sponsor or from regulatory or ethical authorities, where it is relevant to my taking part in research. ☐

I give permission for information concerning my details to be held by Newcastle University. I understand that records will be confidential and will be stored securely on systems within the University. I also give permission for further, future research involving the anonymous data provided. ☐

I understand that anonymous extracts from research recordings and notes may be used in disseminating the project findings. ☐

I understand that if I tell you something that suggests someone is at risk, you will inform the appropriate person, according to Newcastle Upon Tyne Hospitals NHS Foundation Trust safeguarding policy. ☐

I give permission for the interview to be recorded via the zoom record function or audio recorder. ☐

I consent to take part in this study. ☐

Signed.. ………
Date...............................

Consented by……………………………… (signed)
Date...............................

Print name..

8 Confidentiality protocol

Thank you for agreeing to take part in this research project.

Please note that your personal details (email/address/phone number) will always be kept confidential and will only be known by the researcher (Laura Prato). The data you provide during the interview will be anonymised and you will not be identifiable, nor will any person or place you discuss during the interview.

Provisions for disclosing confidential information.

Please be aware that the researcher (Laura Prato) has a duty of care to disclose personal information to the relevant authorities (Police or other emergency services) if during the course of the interview she becomes aware of a risk of harm to yourself or someone close to you.

If you disclose an intention or knowledge of harm to yourself or others, the researcher has a moral, and potentially legal obligation to break confidentiality to protect you or others.

This would also be the case if you disclose information regarding participation in illegal activities.

The researcher (Laura Prato) will discuss the need to break confidentiality with you and ask that you seek the relevant support if you disclose an intention or knowledge of harm to yourself and/or others.

Also, if during an interview there is an immediate risk of self-harm, Laura Prato will ring an ambulance to safeguard your wellbeing.

If during an interview you indicate feelings of depression, Laura Prato will signpost you to your GP, support network and other support services offered by community groups such as Alzheimer’s UK and/or Mind. Laura Prato will seek your permission to contact you the day following the interview to offer further support.

If you disclose illegal activities during an interview, Laura Prato will inform the police.

If adult abuse is disclosed during an interview, Laura Prato will follow local policy and procedures for adult safeguarding which will involve contacting the local authority and making a safeguarding referral.

The researcher will alert Dr Clare Abley (supervisor) and the study sponsor representative and the Dean of Translational and Clinical Research at Newcastle University of the circumstances of the breach of confidentiality for safeguarding purposes and this will be documented.

On request, the researcher (Laura Prato) will provide you with a list of potential support options following the interview if you wish to seek further well-being support.

9 Health Research Authority approval

Dr Clare Abley
Campus for Ageing and Vitality Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk
02 September 2020

Dear Dr Abley

What are the factors that ensure the well being of adults living with dementia and their carers during hospital discharge? A qualitative study focused on factors that health and social care professionals identify as integral, to ensuring the well being of patients living with dementia and their carers, during the discharge process

258329
19/HRA/4265
Organization not set

I am pleased to confirm that **HRA and Health and Care Research Wales (HCRW) Approval** has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The *"After HRA Approval – guidance for sponsors and investigators"* document on the HRA website gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is **258329**. Please quote this on all correspondence.

Yours sincerely,

Email: approvals@hra.nhs.uk

Copy to: **List of Documents**

The final document set assessed and approved by HRA and HCRW Approval is listed below.

10 REC ethical approval

Northwest - Greater Manchester West Research Ethics Committee
Barlow House
3rd Floor
4 Minshull Street
Manchester
M1 3DZ

08 February 2021

Dr Clare Abley
Campus for Ageing and Vitality
Westgate Road
Newcastle Upon Tyne
NE4 6BE

Dear Dr Abley,

Title: Ensuring well-being for people living with dementia and their carers following hospital discharge A qualitative study addressing the physical, social and emotional requirements of patients living with dementia and their carers during and after the hospital discharge process.

REC Reference: 20/NW/0420

IRAS: 287679

Thank you for your submission on 28 January 2021, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair and Lead Reviewer.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral: https://www.hra.nhs.uk/planning-and-improvingresearch/research-planning/research-registration-research-project-identifiers/

If you have not already included registration details in your IRAS application form, you should notify the REC of the registration details as soon as possible.

Further guidance on registration is available at: https://www.hra.nhs.uk/planning-and-improvingresearch/research-planning/transparency-responsibilities/

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: https://www.hra.nhs.uk/planning-and-improving-research/applicationsummaries/research-summaries/

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: https://www.hra.nhs.uk/COVID-19-research/approved-COVID-19-research/

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, Final report
- Reporting results

The latest guidance on these topics can be found at https://www.hra.nhs.uk/approvalsamendments/managing-your-approval/.

Ethical review of research sites

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high-quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/qualityassurance/

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: https://www.hra.nhs.uk/planning-and-improvingresearch/learning/

With the Committee’s best wishes for the success of this project.

Yours sincerely

Email: gmwest.rec@hra.nhs.uk

11 Table of extracted data for systematic review example

Extracted data example for publication				
Author, year	Purpose	Participants	Methodology, data collection and analysis	Key findings
Kadushin and Kulys 1994	To assess how involved patients and families are in the discharge planning process	80 Social Care Professionals	Interviews	Patient safety key factor in discharge planning for social workers and physical needs of care. Goals around discharge most often set by social worker, not by the patient and not if they have cognitive impairment
Jamieson *et al.*, 2016	This study aimed to describe the experience of carers when a patient with dementia transitions home from hospital.	46 carers	30 over the phone interviews and 2 focus groups	The transition to home is difficult due to inconsistent, and often non-existent, discharge planning, resulting in no or delayed access to services.
Kaiser and Kaiser 2017	Case study of the experience of carers' experience during hospitalisation of relative with cognitive impairment	Case study	Case study	The discharge process was rushed and based on availability and not suitability. Appropriate medications were not provided at discharge, the family was not communicated with at discharge, regarding test

				results and the patient's medical condition.
Digby *et al*., 2018	The central research question of the study was "What are the factors which impact on the care of people with dementia in subacute geriatric rehabilitation hospitals?	30 participants	30 conversational interviews with patients with cognitive impairment and 120 hours of ethnographic observations	Person centered care should be used by nurses to ensure that the patient is involved in discharge decisions as patients are currently not given the opportunity to contribute to decision making.
Kaiser and Varghese, 2014	Case study focusing on the poor discharge experience of a patient with dementia	case study	case study	Multiple medication errors made on discharge due to the patient being discharged without acknowledgement of his dementia diagnosis. Healthcare professionals must include carers in discussions of medication changes before discharge as rushed discharges can lead to medication errors for patients with dementia.

Shyu, 2009	To explore the changing needs of family carers of discharged elderly persons during the transition from hospital to home.	16 carers	Interviewed before hospital discharge, two weeks after discharge and one-month post discharge	Family carers reported various discharge needs, including information on the care receiver's condition, symptom monitoring and management, personal care delivery, emergency management, help in mastering personal care skills, handling the care receiver's emotions, making the care receiver compliant, and setting up continuing services, and emotional and manpower support. The needs of family carers during the discharge transition changed over time.
Mockford *et al*, 2015	To explore the experiences of carers and people living with memory loss of hospital discharge	15 carers, 15 patients and 17 health care professionals	15 Interviews with patients/carers. 7 carer diaries. 17 staff interviews. 5 carers attended a focus group.	Requirement for a mutually agreed and meaningful discharge plan a named coordinator point of contact for services and further support needed for carers and patients. Carers and patients are often excluded from the discharge process.

Huby *et al*., 2004	The research aimed to address the lack of understanding of the impact of organizational context on discharge planning and the way this frames opportunities for patients' participation in decision-making.	22 patients. Unspecified number of health and social care professionals	22 patients interviewed in hospital and 11 interviewed post discharge. Health and social care professionals also interviewed. 2 case studies explored in depth	Findings suggested that risk management was a central driver of the discharge planning process, and that risk management and patients' participation were linked in complex ways.
Fitzgerald *et al*., 2011	To understand the family carers' experience of hospital discharge planning and how well the discharge plan, for patients with dementia, meets the needs of the family carer	25 carers	Semi structured interviews with carers	Adhoc and insufficient communication from staff to carer concerning the hospital discharge process. Family carers did not see themselves as involved in the discharge process. Discharge decisions made by health and social care staff.
Cooper and Deeks, 2012	To identify good practice and gaps in hospital admission and discharge medication processes, for patients living with dementia	20 health care professionals from primary and secondary care	Interviews	Identified ineffective communication an issue during discharge, underdeveloped planning processes and no standardised system to identify patients with dementia. Good practice based on

				individual champions and specific good communication practices. Requirement for effective communication and systems between patients, carers, hospital staff and primary care. Further training needed for health care staff around the patient journey.
Gupta *et al*., 2006	To audit a relatives communication clinic during the hospital discharge process	47 Families	Audit	Feedback showed that the multidisciplinary team and trainee health-care professionals benefited from the clinics: for example, it reduced fragmented care plans, helped timely discharge planning and empowered junior staff.
Norman, 2003	To explore the ways in which people with dementia are cared for when admitted to hospital for acute care.	4 focus groups with health professionals (n=26). 8 participants recruited for ward observation. Semi structured	Focus groups, ward observation, semi-structured interviews	The patient with dementia can be reduced to their medical needs during the hospital discharge process, their holistic requirements are not considered.

		post discharge interviews with 4 patients and 3 family members		Relative and/or carer involvement in the discharge process substituted for patient involvement. Considerations of risk undermine patient involvement in hospital discharge decision making.
Telford, 2015	Aim to explore the experiences of people with dementia when they are hospitalized for physical health conditions	8 carers	Interviews	Patients with cognitive impairment were excluded from the hospital discharge decision making process with health and social care professionals often making decisions in isolation. The day of discharge was experienced as unorganized with transport delays having a negative impact on the patient with dementia.
Rhynas *et al.*, 2018	To gain an in-depth understanding of the decision-making processes involved in the discharge of older people	6 patients with cognitive impairment	Narrative case studies were created and were thematically analysed	Patient with cognitive impairment excluded from hospital discharge decision making and felt unable to change decisions made on their

	admitted to hospital from home and discharged to a care home,			behalf. The opinions of family members and carers regarding discharge destination are privileged above patient views. Patients are often objectified in hospital discharge decision making by considerations of risk.
Kuluski *et al*., 2017	To understand the hospital experience of carers patients with alternate levels of care and cognitive impairment who were waiting for long-term care from the hospital	15 carers	12 semi-structured interviews	Hospital pressures to free up bed space leaves patients vulnerable to being discharged before appropriate community resources are identified. Patients reduced to medical needs.
Macmillan, 2016;	To explore the impact of hospital discharge on the wider wellbeing of older people	2 carers for patients with dementia.	Unclear	Patients often discharged without appropriate safeguarding and discharged home without care packages in place.
Bauer *et al*, 2011b	To explore family carers' perceptions of hospital discharge planning and preparation	25 Family carers	Interviews	Discharge planning often adhoc with no formal discharge plan available.

Deeks *et al*, 2016	To explore medication processes in acute care episodes and care transitions for patients with dementia	51 health and social care professionals and carers	Semi structured interviews	Medication management during hospital discharge, for patients with dementia, is suboptimal. Errors in prescribing and administration during discharge present a safeguarding risk. The Lack of an ongoing systematic approach to the medication communication discharge process, presents a governance issue leaving patients at risk.
Redwood *et al*, 2016	To find out what 'home' means to older people and people with memory loss in relation to their sense of identity.	60 participants with dementia and their carers	Interviews	Considerations of risk exclude patients living with dementia from discharge destination decision making. Risk assessment must be balanced with patient desire to be discharged home and professional opinion must not be prioritized. Discharge must not be rushed.

Parliamentary Health Service Ombudsman, 2016	A report of investigations into unsafe discharge from hospital	4 case studies into discharge for patient living with dementia	Complaints	Patients living with dementia are being discharged before they are ready to leave hospital. Patients are not being assessed or consulted appropriately before discharge and are being discharged without discharge care plans, there is a lack of co-ordination in and between health and social care services. Patients are being discharged without proper capacity assessments. There is a lack of safeguarding during the discharge process and discharge is sometimes occurring at night.

Poole *et al*, 2014	How assessments of residence capacity are performed on general hospital wards for patients potentially lacking capacity	35 interviews with health and social care professionals. Twenty-nine patient interviews and 28 interviews with a nominated relative. Ethnographic sessions- 111 days of ward-based field data were collected regarding 29 patient cases. Three focus groups of health and social care professionals (n = 22) and one group of three carers plus two voluntary agency staff members.	Interviews, ethnographies and focus groups.	Patients living with dementia undermined by relatives and health care professionals from taking part in decisions regarding discharge destination due to capacity assessments. Formal assessment outcomes and opinions of professionals privileged above patient opinion.
Kable *et al*., 2015	To report health professionals' perspectives on the discharge process for people with dementia and their carers	33 health and social care professionals	4 focus groups	Poor discharge planning evident for patients living with dementia. Pressure to discharge patients before appropriate due to hospital pressures. Lack of community resources available at discharge. Lack

				of safeguarding in relation to medication management at discharge.
Boaden, 2016	Report into dementia care in hospitals in the UK	FOI request to all trusts and survey of 570 people affected by dementia	Case studies of patients living with dementia during hospital discharge process	Identified often no formal discharge plan available. Discharges at night and rushed discharges common.
Cumbler *et al*; 2008	Case study of patient living with dementia including an analysis of the barriers to successful transition	One patient	Case study	Lack of safeguarding in relation to medication during discharge process. Discharge occurring over the weekend inappropriately
Bauer *et al*, 2011a	To explore whether hospital discharge practices meet the needs of the family carer of a person with dementia.	25 Family carers	Interviews	Adhoc discharge planning and no formalized discharge planning process evident for patients living with dementia
Coleman and Roman, 2015	To explore facilitators and challenges family carers face in assuming post discharge family caregiving roles and completing complex care tasks	32 family carers	Focus groups	Family carers may have different goals to patients living with dementia which may impact on the experience of discharge for the patient.

Dyrstad *et al.*, 2015	To explore older patients' participation during hospital admission and discharge.	41 older patients and relatives	Observations and conversations	Patients excluded from discharge discussions and decision making which took place amongst health care professionals. Patients often discharged inappropriately or too quickly due to hospital pressures and ward routine. Relatives can function as advocates during hospital discharge. Health care professionals can involve patients living with dementia to be involved in discharge decision making. Patients often reduced to medical needs.
Gilmore- Byovski, 2017	To describe skilled nursing facility (SNF) nurses' perspectives on the experiences and needs of persons with dementia (PwD) during hospital-to-SNF transitions	40 nurses	Interviews and focus groups	Patients living with dementia often excluded from the discharge decision making process. Requirement for bed space privileged above patient discharge needs. Organizational needs of hospital placed above

				patient welfare leading to unsafe discharge. Poor discharge planning evident.
Emmett *et al*, 2014	To examine safeguarding role of relatives during hospital stay of patient living with dementia	35 interviews with health and social care professionals. Twenty-nine patient interviews and 28 interviews with a nominated relative. Ethnographic sessions- 111 days of ward-based field data were collected regarding 29 patient cases. Three focus groups of health and social care professionals (n = 22) and one group of three carers plus two voluntary agency staff members.	Interviews, ethnographies and focus groups.	Patients living with dementia often replaced by relatives during discharge planning. Ideas around risk and safety lead to exclusion of patient living with dementia from discharge decision making. Deficiency is community services impacting on hospital discharge process.

12 Extraction example for systematic review

Heading	Detail	A Relative Safeguard? The Informal Roles that Families and Carers Play when Patients with Dementia are Discharged from Hospital into Care in England and Wales
Bibliographic details		Charlotte Emmett,*,† Marie Poole,** John Bond,** and Julian C. Hughes*** 2014
		International Journal of Law, Policy and The Family
Name of Reviewer		LP
Eligible	Does the evidence fit within the scope of the review? Is it quantitative only? Or professional data only?	Qual
Reviewer rating	Matrix	
Typology	A systematic or literature review? Case study? Primary research? Descriptive?	Primary research. Over a period of 9 months between June 2008 and June 2009 (including a 3-month analysis period at 6 months), 111 days of ward-based field data were collected. Fieldwork was undertaken on three general elderly care wards, in two hospitals within two NHS healthcare trusts in the north-east of England. Fieldwork centred on the care and discharge process of 29 patient cases. In total, 92 formalized qualitative in-depth interviews were conducted with all stakeholders. The 35 interviews with health and social care professionals represent perspectives from a broad range of disciplines and include: senior and junior doctors (physicians and psychiatrists); nursing staff (qualified and non-qualified, senior and junior, and psychiatry liaison); social workers; occupational therapists, a physiotherapist, and an IMCA. Twenty-nine patient interviews and 28 interviews with a nominated relative were conducted at the

		point of discharge and at 3 months post discharge where possible.
Participants	Evidence from service users, carers, policy or practice?	A series of focus groups were conducted between April and May 2009 to incorporate a broader range of views, values and experiences. Participants were asked to suggest if and how residential capacity and best-interest decisions could be improved through discussing hypothetical vignettes derived from the ward-based data. Three groups of health and social care professionals (n ¼ 22) and one group of three carers plus two voluntary agency staff members participated. Professional participants were represented by: general practitioners (including a trainee); social workers; occupational therapists; nurses (including a nursing home placement assessor); psychologists, a chaplain; and a care home manager
Study aims	What were the aims and purpose?	It is from this premise that we set out to explore, through our data, the informal role of relatives during the discharge-planning process and the extent to which they do, in fact, fulfil an effective safeguarding role when decisions are made to discharge older patients with dementia from hospital either back home or into long-term care. It is through this enquiry that we hope to develop a clearer picture of how the MCA is being implemented in practice and the extent to which the current statutory framework of the MCA is effective in safeguarding the rights of incapacitated older people.

Key findings	What are the key findings of the study?	Themes have been grouped under three headings, namely: the different informal roles that relatives play during discharge from hospital (including the assumption of a caretaking or safeguarding role); the potential barriers that may prevent relatives from carrying out an effective safeguarding role during discharge planning; and those positive factors which helped relatives to safeguard the interests of dementia patients during discharge.
Evaluative summary	Draw together brief comments on the study as a whole and its strengths and weaknesses. Is further work required? What are its implications for policy, practice and theory, if any?	Broad range of methods with professionals, carers and patients.
Service users' and carers' perspective	Does the study report on the experience of service users? Does the study report on the experience of carers? How were they involved in the study (e.g. as advisors for the research, in the design and execution of the study, in dissemination)?	See above
Ethical Approval	Was ethical committee approval obtained? Was informed consent obtained? Does the study address ethical issues adequately? Has confidentiality been maintained	Ethics apparent

Aims	Are the aims and purpose of the study clearly stated?	Clear above
Setting	What is the geographical and care setting for the study?	see above
Rationale	What is the rationale and appropriateness for this choice?	
Detail	Is there sufficient detail about the setting?	
Timing	Over what period did the data collection take place?	see above
Sample	Inclusion criteria	Mixed criteria
	Exclusion criteria	
Selection	How was the sample selected? Were there factors that influenced how the sample was selected? ACCESS/TIMESCALES ETC	Not clear re focus groups Participating wards were selected based on specialism and case-mix (care of the elderly and ortho-geriatric care, including acute and rehabilitation settings). The broad inclusion criteria adopted in the study reflected the naturalistic approach to enquiry and the underpinning patient-centred ethos of gaining perspectives of patients with dementia regardless of advancement of the condition. Therefore, both patients who were able and unable to consent to participation were included. Personal and nominated consultee agreement was obtained for those patients whom the researcher considered unable to provide written consent. A member of the clinical team made the initial approach to the patients, which the researcher then followed up. Contact with relatives was established through the patients. Cases were then theoretically sampled (Silverman, 2005) to ensure participants represented a broad range of characteristics including: reason for admission; living

		arrangements; formal and informal support networks; capacity decision and discharge outcome. The sample also extended to represent key events and interactions which characterized cases such as discharge planning meetings; home visits and input from psychiatry services. Ward staff consented to be observed, and professionals were purposively sampled for an additional qualitative interview
size	What was the size of the sample and groups within the sample?	see above
Appropriateness	Is the sample appropriate in terms of its ability to meet the aims of the study? The depth and breadth of data collected?	Breadth
Data collection	Methods: what data collection methods were used? Was the data collection adequately described and rigorously conducted?	See above variable, topic guides for interviews discussed alongside the ethnographic process
Role of researcher	What is the role of the researcher? Are there any conflicts of interest potentially?	Not clear but clinical team recruitment
Fieldwork	Is the process of the fieldwork adequately described?	yes
Data analysis	How are the data analysed? How adequate is the description of the data analysis? Is adequate evidence provided to support the analysis (e.g. use the	Analysis of coded transcripts was conducted through a series of data workshops (MP, JB, and JCH). This facilitated the development of a coding framework for all data, from which themes emerged. Emergent themes were further developed through the use of memos leading to key concepts in the data (Charmaz,

	original data, iterative analysis, efforts to prove validity and reliability) Is the study set in the context in terms of findings and relevant theory?	2006). Data was managed using NVIVO software (NVivo, 2010). For each of the 29 cases, the multiple sources of field data were synthesized into 'case studies' of decision-making processes relating to judgments on capacity and discharge. Using constant comparative methods (Glaser and Strauss, 1967), case studies were then analysed highlighting similarities and differences. This allowed common themes and key differences to emerge between cases, indicating examples of good practice or potential areas for improvement in the processes of assessment of residence capacity, best-interest judgments, and discharge.
Researchers potential bias	Are the researchers own positions and bias outlined? Indicate how they could affect the study in terms of analysis and interpretation of data?	no
Reflexivity	Are the findings substantiated by the data and has consideration been given to any limitations of the methods that may have affected results?	Extensive detail and quotations
Outcomes	What outcome measures were adopted? What was the impact of the study for service users? Carers? Practicioners? Organizations responsible for services?	

Findings	Themes	Frequently relatives took on informal roles assisting older patients with daily living, facilitating communication between the patient and health and social care staff, which enhanced an older person’s welfare and decisional abilities on hospital wards (Boyle, 2013). Relatives acted as advocates for patients who were too ill or confused to articulate their own views and wishes: INT:…my wife’s done most of the talking you see ‘cos I’ve been in hospital. She’s done most of the talking. (Interview: 021208, lines 142–143: Patient (Mr Coleman)). During their interactions with health and social care professionals, relatives also acted as information gatherers, questioners, observers, and prompters. However, not all relatives we observed were proactive information-gathers, often reluctant to interfere with hospital protocols or to question professional views (Efraimsson et al., 2006). Also, while the IMCA had a statutory right of access to a patient’s medical and social care records, which provided her with important background clinical and social information concerning the patient, relatives often found it difficult to access clinical information in hospitals. This may have been due to issues surrounding patient confidentiality, poor communication by professionals or relatives simply not knowing where to access the required information. A. Lack of Information and ‘Signposting’ by Professionals Although we observed that decisions about discharge were made in other contexts (such as ward rounds, informal meetings between staff, patients, and relatives), we found that discharge planning meetings (otherwise known as case conferences) often provided the formal venue for best-interests decision-

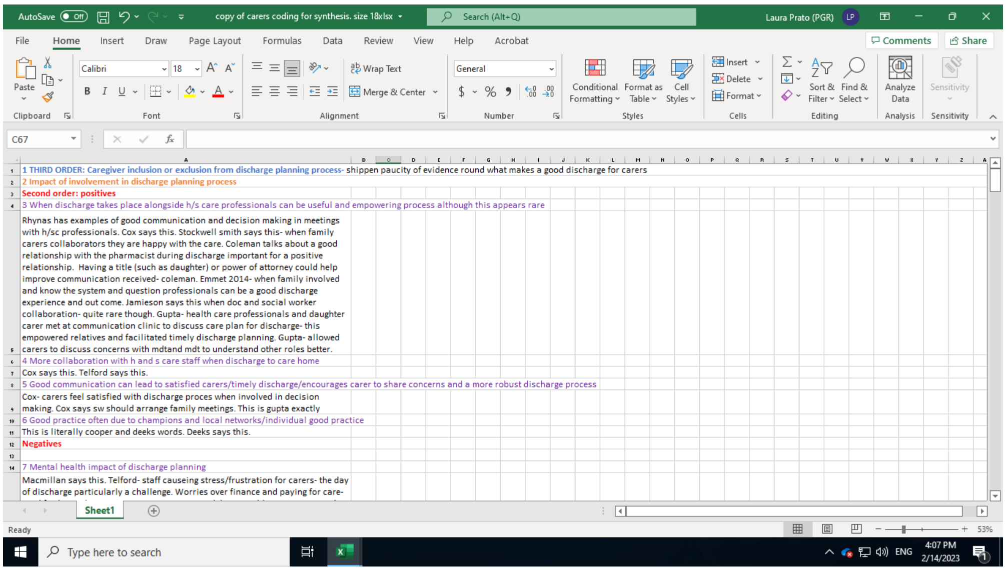
		making prior to discharge. However, relatives were not always aware of the purpose of those discharge planning meetings, which were not always properly signposted by professionals as being relevant to discharge placement. Several relatives also expressed concerns that they had not been given enough timely information by professionals to be fully informed and prepared for discharge planning meetings. As such, they felt that they were not adequately prepared to make informed judgments about where patients should live on discharge, or to challenge professional views when they felt this was necessary. The ability of relatives to represent and safeguard a patient’s best interests was also called into question when conflicts of interests arose between relatives and patients. In the extract below, one junior doctor alludes to the difficulties faced by Mrs Salter’s daughter who had to uncouple her own interests (that her mother’s home, which she saw as her inheritance, was to be used to pay for a private care home placement) from the best interests of the patient. C. Inequalities of Power Older or less assertive relatives found it difficult for their voices to be heard in the discharge-planning process or to influence and challenge discharge outcomes, even when they thought this was necessary. Inequalities of power in the decision-making process were occasionally the result of a relative’s perceived deference to professional opinion or hospital procedures, or the desire to conform to the views of stronger willed, more coercive family members. The result was that many relatives appeared to be ill-equipped to safeguard patients’ best interests. This extract suggests how easy it can be for decisions to

		become ‘medicalized’ by professionals when they are privy to clinical information that relatives are not party to, with the result that relatives can suddenly become excluded from the decision-making process- see quote for professional making the decison over relative. ‘you can’t look after him’, ‘pardon’, ‘you can’t look after him,’ I said ‘but why?’ ‘well you know he’s got short term [memory loss],’ I says, ‘well I know that’ [mmh mmh] ‘I know but he’s got to be turned over three times through the night’, ‘what’, ‘he can’t turn himself over’. So straight out of my hands then.' Relatives also struggled to carry out effective safeguarding roles at a time when they were often coming to terms with the emotional stress and burdens associated with their close relative or spouse being suddenly admitted to hospital, and the potential impact that any discharge decision would have on their own lives.
	Conclusions	Frequently, decisions about changes of accommodation will be made suddenly in an older person’s life, during ‘the crisis of hospitalisation’ (McAuley et al., 1997) and often when a patient’s cognitive abilities and health are fluctuating. Professionals have the difficult job of weighing and ranking complex clinical needs alongside competing personal, social, and ethical factors, where issues of risks (to the patient and to others) will often weigh heavily in any placement decision made (Emmett et al., 2013; Greener et al., 2012). Family and close friends – most often the primary carers in older patients’ lives – may wish to assert their own personal agendas, so that conflicts of interest can arise between patients and their carers (Brindle and Holmes, 2005). Typically, older people with

		dementia fade into the background during this decision-making process, while others decide on their relocation into permanent care (Dwyer, 2005). Moreover, decisions about hospital discharge and living arrangements are inextricably linked with diminishing community services and finite hospital resources, where ‘effective bed management’ and ‘improving patient throughput’ have become common bywords in hospital discharge planning (Banerjee et al., 2008). This can lead to ill-conceived capacity assessments being carried out by professionals on busy hospital wards and best-interests decisions that fail to comply with the legal standards of the MCA (Emmett et al., 2013).
opinions	What is argued?	see above
Policy and practice	Generalizability: To what extent are findings generalisable? What is the country of study? How applicable are the findings to the UK system? Are the conclusions justified?	UK
Implications for policy	What are the implications for policy?	see above
Implications for practice	What are the implications for practice?	see above
Other comments	Format	
Links to references to follow up		
Decisions	second reviewer name	
agreement with reviewer		yes
Inclusion	Should this be included?	
Topic question	date	4/8/2019

Date	casp	yes

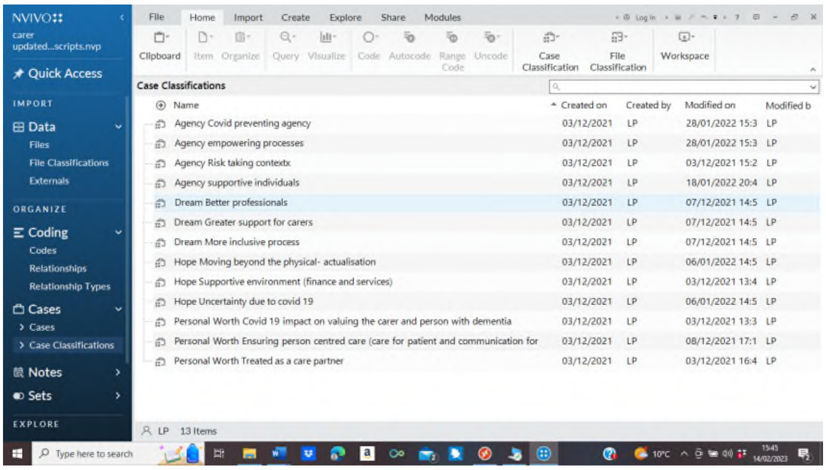
13 Example systematic review synthesis



	A
1	**1 THIRD ORDER: Caregiver inclusion or exclusion from discharge planning process-** shippen paucity of evidence round what makes a good discharge for carers
2	**2 Impact of involvement in discharge planning process**
3	**Second order: positives**
4	3 When discharge takes place alongside h/s care professionals can be useful and empowering process although this appears rare
5	Rhynas has examples of good communication and decision making in meetings with h/sc professionals. Cox says this. Stockwell smith says this- when family carers collaborators they are happy with the care. Coleman talks about a good relationship with the pharmacist during discharge important for a positive relationship. Having a title (such as daughter) or power of attorney could help improve communication received- coleman. Emmet 2014- when family involved and know the system and question professionals can be a good discharge experience and out come. Jamieson says this when doc and social worker collaboration- quite rare though. Gupta- health care professionals and daughter carer met at communication clinic to discuss care plan for discharge- this empowered relatives and facilitated timely discharge planning. Gupta- allowed carers to discuss concerns with mdtand mdt to understand other roles better.
6	4 More collaboration with h and s care staff when discharge to care home
7	Cox says this. Telford says this.
8	5 Good communication can lead to satisfied carers/timely discharge/encourages carer to share concerns and a more robust discharge process
9	Cox- carers feel satisfied with discharge proces when involved in decision making. Cox says sw should arrange family meetings. This is gupta exactly
10	6 Good practice often due to champions and local networks/individual good practice
11	This is literally cooper and deeks words. Deeks says this.
12	**Negatives**
13	
14	7 Mental health impact of discharge planning
	Macmillan says this. Telford- staff causeing stress/frustration for carers- the day of discharge particularly a challenge. Worries over finance and paying for care-

14 NVIVO coding example

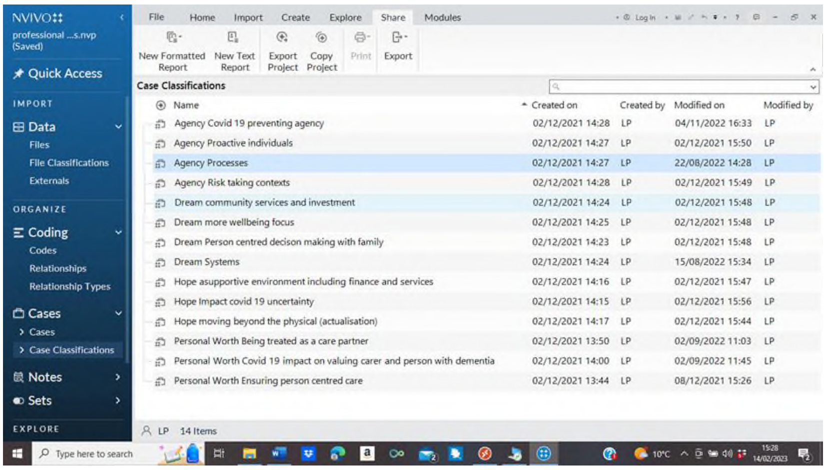
Professional and Carer transcript coding



Case Classifications

Name	Created on	Created by	Modified on	Modified b
Agency Covid preventing agency	03/12/2021	LP	28/01/2022 15:3	LP
Agency empowering processes	03/12/2021	LP	28/01/2022 15:3	LP
Agency Risk taking contextx	03/12/2021	LP	03/12/2021 15:2	LP
Agency supportive individuals	03/12/2021	LP	18/01/2022 20:4	LP
Dream Better professionals	03/12/2021	LP	07/12/2021 14:5	LP
Dream Greater support for carers	03/12/2021	LP	07/12/2021 14:5	LP
Dream More inclusive process	03/12/2021	LP	07/12/2021 14:5	LP
Hope Moving beyond the physical- actualisation	03/12/2021	LP	06/01/2022 14:5	LP
Hope Supportive environment (finance and services)	03/12/2021	LP	03/12/2021 13:4	LP
Hope Uncertainty due to covid 19	03/12/2021	LP	06/01/2022 14:5	LP
Personal Worth Covid 19 impact on valuing the carer and person with dementia	03/12/2021	LP	03/12/2021 13:3	LP
Personal Worth Ensuring person centred care (care for patient and communication for	03/12/2021	LP	08/12/2021 17:1	LP
Personal Worth Treated as a care partner	03/12/2021	LP	03/12/2021 16:4	LP

LP 13 Items

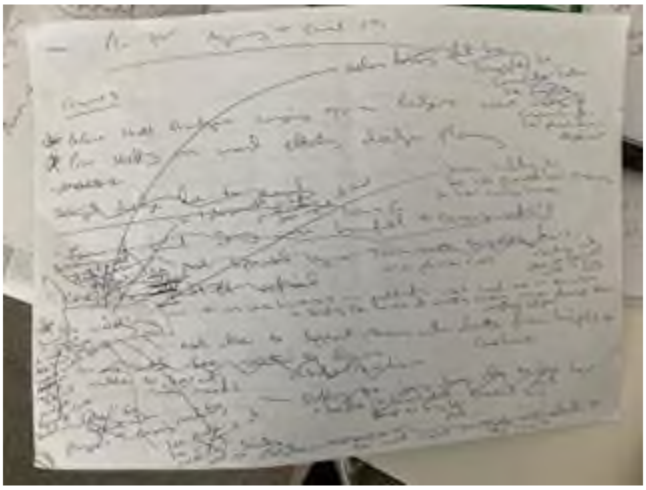


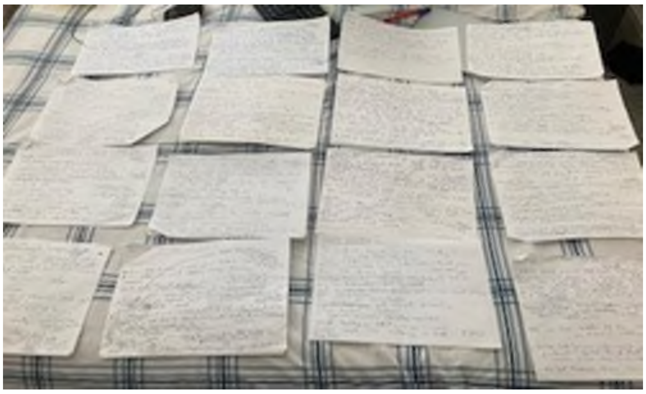
Case Classifications

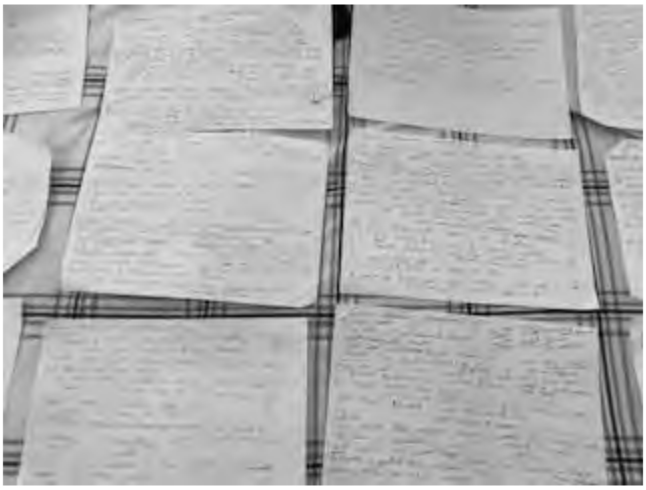
Name	Created on	Created by	Modified on	Modified by
Agency Covid 19 preventing agency	02/12/2021 14:28	LP	04/11/2022 16:33	LP
Agency Proactive individuals	02/12/2021 14:27	LP	02/12/2021 15:50	LP
Agency Processes	02/12/2021 14:27	LP	22/08/2022 14:28	LP
Agency Risk taking contexts	02/12/2021 14:28	LP	02/12/2021 15:49	LP
Dream community services and investment	02/12/2021 14:24	LP	02/12/2021 15:48	LP
Dream more wellbeing focus	02/12/2021 14:25	LP	02/12/2021 15:48	LP
Dream Person centred decison making with family	02/12/2021 14:23	LP	02/12/2021 15:48	LP
Dream Systems	02/12/2021 14:24	LP	15/08/2022 15:34	LP
Hope asupportive environment including finance and services	02/12/2021 14:16	LP	02/12/2021 15:47	LP
Hope Impact covid 19 uncertainty	02/12/2021 14:15	LP	02/12/2021 15:56	LP
Hope moving beyond the physical (actualisation)	02/12/2021 14:17	LP	02/12/2021 15:44	LP
Personal Worth Being treated as a care partner	02/12/2021 13:50	LP	02/09/2022 11:03	LP
Personal Worth Covid 19 impact on valuing carer and person with dementia	02/12/2021 14:00	LP	02/09/2022 11:45	LP
Personal Worth Ensuring person centred care	02/12/2021 13:44	LP	08/12/2021 15:26	LP

LP 14 Items

15 Examples of hand coding







16 Plan for systematic review

Background

The World Alzheimer's Report (2016) called for the opinions of those with dementia and their carers to be more integrated into research around care models and decisions in relation to the commissioning of services. The report (World Alzheimer's Report, 2016) identified that the role of the professional dementia specialist will become vital in the coming decades as the prevalence of dementia rises (World Health Organisation, 2015) and more general health professionals will need to develop their knowledge and skillset. According to Alzheimer's Society (2014) 7% of population over 65 have dementia, over 1 million people by 2025. It has been acknowledged that more information on carer and patient experiences of dementia and specialist dementia nursing services which can be hospital or community based. To consider the acceptability to carers for adults with a dementia diagnosis of the acceptability of community-based specialist nursing services. Alzheimer's Research UK (2015) says impact on carers is immense and need further research on interventions to help carers cope with caring for loved ones in the community. The challenges faced by carers are varied and include emotional strain as well as managing the practicalities of caring for adults with dementia (Feast *et al.*, 2016). Research has suggested that partnership working (Bunn *et al.*, 2017) facilitated by specialist teams in the community could lead to improvements in carer satisfaction and the quality of services available for community dwelling patients with dementia and their carers. Some research (Moniz-Cook *et al.*, 2008) has suggested that a community-based nurse with specialist knowledge of dementia care can have a positive impact on carer experiences. Other research (Robinson *et al.*, 2010) has suggested that increasing skill mix in community primary care teams to include specialist nurses would result in more holistic care models and practices. It has been recognised that further development of the community dementia specialist nurse role is required to ensure the success of the post (Page and Hope, 2013). A systematic review (Bunn *et al.*, 2016) was carried out in 2012 to assess the effectiveness and scope of admiral nurses which found that all community support for carers of older people with dementia was valued by those carers. This systematic review will differ from and build upon the 2012 review, as it will broaden the scope from just admiral nurses and the focus will be upon the experience of carers, rather than the potential effectiveness of services. The authors verified that no other systematic review into this topic area is currently registered on the PROSPERO (University of York Centre for Reviews and Dissemination, 2017) website.

Aims/objectives.

The aim of this review is to synthesise the opinions and experiences of carers and individuals with a dementia diagnosis of community-based specialist dementia nursing services. Researchers aim to identify the acceptability of community-based specialist dementia nursing services for carers and adults with a dementia diagnosis and identify the positive or negative experiences of receiving support from specialised nursing teams.

The review question.

What are the experiences and opinions of carers and individuals with a dementia diagnosis living at home of community-based specialist dementia nursing services?

Search Strategy Methods

The **SPIDER** (Alison *et al.*, 2012) method was used to devise an appropriate question. I will use, truncation, Boolean operators, nesting and use the filters available in each different type of search engine (Booth, 2016). I will identify all synonyms and consult the MESH terms (US National Library of Medicine, 2017) to identify all possible search words. Details of the search strategy development will be documented. The search strategy question designed for use in searching the electronic data bases is detailed below:

Sample: Carer* OR Family* OR Relative* OR patient* OR dementia diagnosis

Phenomena of Interest: Community Specialist dementia nurs* OR Community Dementia nurs* OR specialist dementia servic*

Design: Interview* OR Focus group* OR Survey* OR Questionnaire* OR Ethnography*

Evaluation: View* OR Experience* OR Perspective* OR Attitude* OR Opinion* OR Belief* OR Thought*

Research type: Qualitative

Electronic databases: Proquest Social Sciences Premium Collection; Scopus; Web of science; MEDLINE; CINAHL; EMBASE; PsychInfo

Researcher will also us ‘snowball’ searching to identify grey literature and liaise with supervisors to identify further literature. Journal article reference lists will be hand searched to prevent any literature being overlooked in this process. I will also search Google Scholar.

Inclusion criteria

1 Studies must be in in English. This is for practical reasons as researchers do not have access to translators.

2 Qualitative methodology can include: focus groups; interviews, surveys, ethnographies

3 Must have been published between 1990 and 2017 to ensure that results are relevant to modern evidence-based era of health care research

4 Studies must be based in the community and individuals with dementia must be living at home

Exclusion criteria

1 Quantitative methodology research studies such as: randomised controlled trials; cohort studies and before and after studies

2 Studies published in languages other than English.

3 Studies based in the hospital setting or nursing home.

Search strategy / study selection.

All results from the data base searches will be entered into endnote X7 where one researcher will review all titles and abstracts against the inclusion and exclusion criteria. 20% of the returned results shall be reviewed by a second researcher to ensure the reliability of the primary researcher sifting. If there is no consensus, the primary researcher will re-examine the titles and abstracts and review with the second researcher. The two researchers shall review all included studies once available. A third researcher shall be involved if consensus cannot be reached by the first and second reviewer. Results shall be grouped into included and excluded and the physical copies ordered through the library or downloaded online.

Data extraction

Once paper copies of the studies included have been obtained, data will be extracted by one researcher using a data extraction form developed in accordance with guidance in Noyes and Lewin (2011) and Munro *et al.* (2007). Data to be extracted will include: country, title, authors, aims of study, ethical approval and considerations, study setting, theoretical background of study, sampling approach, participant characteristics, data collection methods, data analysis, key themes identified, recommendations made by authors and authors assessment of study quality, including identified limitations (Munro *et al.*, 2007). 20% of the data extraction forms will be assessed by a second researcher to ensure quality control. The researcher will repeat the process if the forms are judged to be unacceptable by the second researcher. A table shall be created detailing the specifics of each study.

Quality assessment- risk of bias

The CASP tool for qualitative research (Critical Appraisal Skills Programme, 2017) will be used to assess the risk of bias in each of the studies and to ensure that transparency of method is evident in each of the studies to be included. One researcher will complete the quality assessment process and another researcher will review 20% of the completed CASP tools to ensure the reliability and validity of all included studies. A section of the output to be disseminated will explore the risk of bias identified in the studies through the use of the CASP tool for qualitative research. A table shall also be included in the final output detailing author bias risk findings.

Coding and Synthesis Analysis of subgroups or subsets

Researchers will use meta-ethnography (Britten *et al.*, 2002) to identify and synthesis the experiences and opinions identified in the literature. The key researcher shall read through each of the studies multiple times. The researcher will analyse the identified literature using the procedure outlined in Noblit and Hare (1988) by identifying reoccurring concepts and metaphors across the studies. These concepts shall be entered into a table to illuminate the studies relationships to each other. The studies shall then be translated into one another if possible to further illustrate key concepts.

Interpretations shall be developed arising from the concepts identified (Britten *et al.*, 2002) and researchers will utilise published guidance in the development of a meta-ethnography (Lee *et al.*, 2015). Researchers will develop separate subgroup synthesis for carers and individuals with a dementia diagnosis to illuminate the findings for each subgroup. The author believes that Meta-ethnography will be the most appropriate method for analysis and synthesis as the method of comparing and translating studies ensures that findings are emerging across the studies and allows for a true synthesis of findings (Britten *et al.*, 2002). The authors supervisor shall review the tables emerging from the analysis and the subsequent synthesis and comment on the validity of the final output. Any disagreements between the author and the supervisor shall be resolved with reference to a third researcher.

Dissemination plan

Results shall be disseminated through publication in a relevant journal and attendance at an international conference. Potential audiences include: medical professionals; community health care commissioners; stakeholders including carers and individuals with dementia; health care researchers and charities. Researchers believe that the findings will have international significance to policy as they will not be confined to the UK setting only.

People and roles

The author shall conduct the search strategy, data extraction, quality assessment and synthesis with the author's supervisor assisting with the 20% quality assessment, data extraction and sifting being completed by the author's supervisor to ensure that the authors work is accurate.

Timetable

November: Devise search strategy in consultation with specialist librarian

December: Conduct searches of specialist electronic databases. Search strategy to be adjusted if results unmanageable. All results to be entered into Endnote X7 for sifting to begin.

January- March: Sifting to occur. Supervisor to check agreement on 20% of results. Once completed, all included results to be acquired via library if necessary.

April- June: Data extraction and quality assessment to be completed. Supervisor to check 20% of extracted forms and completed CASP tools.

July: First draft of meta-ethnography to be completed.

August: Final draft of meta-ethnography to be completed and publication output to be in draft stage.

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17 Systematic review protocol

Primary question

What are the experiences of patients living with dementia and their familial carers, during the hospital discharge planning process?

Secondary question

What are the key factors that should guide health care professionals in safeguarding the wellbeing of patients and carers of adults living with dementia, during the discharge planning process from hospital?

Aim

To identify and synthesise available evidence, in regards to the experiences of patients living with dementia and their familial carers, during the hospital discharge planning process.

Objectives

- To identity the key factors that impact on the discharge from hospital process experience, for patients and carers of adults living with dementia, through the completion of a systematic review
- To identity any omissions in the evidence base, regarding the experience of patients living with dementia and their carers during the hospital discharge process
- To identify the principles that should guide health care professionals, in their support of physical, emotional and social wellbeing during the hospital discharge process, for adults living with dementia and their carers

Method

Systematic Review

Searches

Search strategies:

Both published and unpublished or grey literature will be included in the systematic review. The following sources will be searched to identify published literature:

Ovid MEDLINE(R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE(R) 1946 to Present Embase (Ovid)
CINAHL (EBSCO)
PsycINFO
Scopus
SCIE: Social Care Online
Pubmed
Proquest
Cochrane
Web of Science

The SPIDER framework has been used to develop the search strategy.

Spider framework	
Sample	**Patients, health and social care professionals and carers of adults with cognitive impairment**
Phenomena of Interest	**Discharge from hospital process for patients and carers/relatives**
Design	**Questionnaire, survey, interviews, focus groups, case studies, ethnographies, observational studies, reviews,**
Evaluation	**Experiences**
Research Type	**Qualitative, mixed methods**

Table 2 Inclusion and Exclusion Criteria beyond spider framework

	Inclusion Criteria	**Exclusion Criteria**
Publication	**Peer reviewed journal research, reports, audits, conference proceedings, unpublished thesis, reviews, systematic reviews**	**Opinion pieces, editorials**

Language	**English language**	**Any other language**

The search terms include:

Sample (patient)	Sample (carer)	Sample (Dementia)	(Phenomena of Interest) Discharge from hospital	Evaluation (Experiences)	Design
Adult	Family	Dementia*	Return home process	Perception	Qualitative
In-patient	Relative	Cognitive Impairment	Leaving hospital	Perspective	Mixed methods
Patient	Care*	Confusion	Discharge planning	View	Realist
	Family Caregive*	Alzheimer's		Need	
	Family care*	Frontal temporal lobe dementia		Experience	
	Informal care*			Insight	
	Care-give*			Opinion	
	Spouse/wife/husband				
	Child/daughter/son/grandchild				

The following sources will be used to identify published literature:

- Electronic databases of peer-reviewed journal articles, including those covering biomedicine, nursing and allied health professions and the social sciences
- Reference lists of all studies meeting the inclusion criteria

Each database will be searched by LP, in conjunction with a librarian. Each column in the search terms table, contains synonyms for the key search terms. Each term in the column will be entered into the database and truncated where appropriate. All individual searches for each column will be combined using the "OR" Boolean operator. The 'AND' function will then be used to combine the terms to create a list of references, which will be saved into Endnote, and screened for duplicates. Records of all searches from the databases will be maintained.

Language

Must have an English language title and abstract

Date Range

All studies from 1990. The principles and understanding of care for adults living with dementia, have changed dramatically since 1990, following the seminal work of Tom Kitwood. Studies after 1990 will reflect current best practice, for the care of adults living with dementia in hospital.

Type of study to be included

Primary research studies that are qualitative or mixed methods will be included as well as relevant reviews.

Type of study to be included

Exclusion: professional discussion, opinion pieces, randomised controlled trials with no qualitative aspect, non-research and all purely quantitative research.

Design to be included

Questionnaire, survey, interviews, focus groups, case studies, ethnographies, observational studies.

Phenomena of Interest

The discharge from hospital planning process.

Includes: all aspects of care and experiences of patients living with dementia and their carers, during the discharge process from hospital, included but not restricted to:

- Nursing care, including person-centred approaches
- Behavioural / psycho-social interventions
- Organisation of care e.g. systems and processes of care delivery
- Staff factors
- Environmental design

Exclusion: discharge from care homes/nursing home settings and discharge experiences for patients without cognitive impairment.

Comparator(s)/ control

None

Context

In-patient and out-patient wards and departments within hospitals and hospices, including (but not restricted to) acute, community hospital, rehabilitation settings and emergency departments.

Evaluation

Patient and carer experiences including:

- Staff-patient-carer communication and factors
- Involvement in discharge planning process
- Multi-disciplinary working outcomes
- Organisational factors
- Safety outcomes

Data Screening

Step 1: Titles and/or abstracts of studies, retrieved using the search strategy and those from additional sources, will be screened by two review authors and studies that do not meet the inclusion criteria shall be excluded. The second reviewer will screen 20% of the results. Decisions about inclusion and exclusion of studies, shall be decided in a series of meetings between the two reviewers.

Step 2: The full text of eligible studies will be retrieved and assessed in full. If it is unclear whether an article is suitable for inclusion, an attempt to contact the author shall be made. If a response is not forthcoming within two weeks, the article shall be discarded and the reason recorded.

The review process will use two reviewers: one research student and a supervisor.

Data Extraction

Reviewer will extract study data using a customised electronic data extraction form, tailored to the qualitative systematic review methodology. The tool will be piloted on 3 articles and will be subsequently modified as required. The data extracted will include: review authors; title and year; aim; study design; participant information (includes staff, carer or patient); inclusion and exclusion criteria; setting; design; summary of content and findings including themes; quotes; strengths and limitations; recommendations and reviewer comments.

Risk of bias (quality) assessment

Risk of bias and the methodological quality of each study will be assessed using standardised published tools. The Critical Appraisal Skills Program (CASP) tool tailored to the type of research assessed shall be used. It is hypothesised that the limited amount of research available, may entail that the quality of the studies retrieved will be restricted. Therefore, all data which illuminates the experience of patients with a dementia diagnosis and their carers, during the discharge from hospital planning process will be included.

No studies will be excluded from the review based on the quality appraisal but reference will be made to study quality, during the synthesis of findings and reporting of the review.

Strategy for data synthesis

Ethnographic synthesis will be undertaken, incorporating interpretive synthesis. Ethnographic synthesis will allow the identification of themes arising from the data and facilitate higher order abstraction and theory development. The method outlined in Noblit *et al.* (1988) and demonstrated by Campbell *et al.* (2003) and Britten *et al.* (2002) shall be utilised during this process, as outlined below.

1) Getting started
2) Deciding what is relevant to the initial interest
3) Reading the studies
4) Determining how the studies are related
5) Translating the studies into one another
6) Synthesising translations
7) Expressing the synthesis

Analysis of subgroups or subsets

None planned

Dissemination plans

Plan to publish in peer reviewed journals, create practitioner-friendly summaries and present at national conferences.

Anticipated or actual start date

December 2018

Anticipated completion date

End of October 2020

Funding source / sponsor

ESRC NINE DTP

Conflicts of interest

None

Other registration details

Country

UK

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