

**‘Being’ a Ventricular Assist Device Recipient: A Liminal
Existence**

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Abstract

The purpose of this thesis is to illuminate the experience of living with a ventricular assist device (VAD) from the perspective of the recipients themselves, specific focus is given to the implications of the device on recipients' day-to-day lives. VADs are mechanical circulatory devices that support or replace the function of a failing heart. In the UK, they are used to bridge patients to heart transplantation. This study adopts an interpretive phenomenological approach using the 'lived experiences' of VAD recipients as the basis of the investigation. The study comprised of twenty patients living with VADs, seventeen men and three women, aged 21 to 68, all of whom had been living on VAD support for varying amounts of time. A central tenet of this thesis is that the experience of 'Being' a VAD recipient is underpinned by a high degree of liminality (Turner, 1969). Life, for these individuals appears to be placed on hold whilst living with the device. Liminality creeps into the experience of 'Being' a VAD recipient at different time points, influencing how the individual views themselves and their future, the practices employed by VAD recipients to manage this uncertainty are considered. The impact of the materiality of the VAD is also discussed, with reference to literature from science and technology studies, exploring how recipients make sense of having a piece of technology implanted into the body and the resultant impacts on identity and surroundings following this merging of the 'self' and 'not-self'. The impact of the VAD on recipients' social roles and responsibilities are explored, along with the role of VAD communities in learning to live with the device. Ultimately, this thesis suggests that the essence of 'Being' a VAD recipient is a pervading sense of liminality as these individuals live under the lingering shadow of heart failure.

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1

Introduction

1. Introduction

This thesis explores the experience of living with a ventricular assist device (VAD¹). The focus of the PhD project is to explore what it means to ‘Be’ a VAD recipient. This study seeks to go beyond the understanding that can be achieved by clinical outcomes and quality of life measures, to provide a phenomenological account of the essence of the experience. My study group comprised of 20 individuals who had received a VAD to support their failing heart, and 11 partners and carers. A variety of VAD recipients were interviewed to gain as full a sense of the experience of living with a VAD as possible. This study explores VAD recipients’ experiences from the receipt of the device, to the reality of the device in everyday life, and contemplation of the future. What follows is a phenomenological account of what it means to ‘Be’ a VAD recipient.

This first chapter acts as an introduction to the thesis, it aims to contextualise my research and situate it within the field of medical sociology. The background information provided in this chapter is an important reference point for some of the issues discussed later in the thesis. I begin with an overview of advanced heart failure as a condition and its prevalence in the UK; I then position VADs as a treatment for heart failure against other interventions. In particular, I focus on the interaction between VADs and heart transplantation, as these two treatments are inextricably linked; I provide an outline of the history and development of both. This is followed by an in-depth introduction to VADs; this includes an explanation of the technology itself, the implantation procedure and the management of the device. Attention is then turned to the commissioning of the devices and the current role of VADs as a treatment in the UK health system. This chapter concludes with an overview of the structure of the thesis.

1.1 Heart failure

Heart disease is one of the largest causes of death in the Western world (Scarborough et al. 2010). This thesis is concerned specifically with heart failure. Heart failure occurs when the efficiency of the pumping function of the heart is impaired (NICE, 2010). Heart failure usually occurs because the heart has been damaged to some degree, for example from a previous myocardial infarction or coronary artery disease (ibid.). The New York Heart Association outlines four stages of classification for heart failure, stages three and four are characterised as advanced heart failure. Patients with stage three heart failure experience a marked limitation in physical activity, the patient is comfortable at rest but less than ordinary physical activity may result in fatigue, palpitations,

¹ See appendix 1 for glossary of terms.

dyspnoea or angina pain. Stage four patients are unable to carry out any physical activity without experiencing discomfort and symptoms are present even at rest (American Heart Association, 2014). Advanced or chronic heart failure has a poor prognosis with 30-40% of patients deceased within a year of diagnosis, although this drops to 10% following a year (NICE, 2010). To contextualise the prognosis of advanced heart failure against other diseases, the chance of surviving to five years with severe heart failure is lower than most types of cancer (British Heart Foundation, 2015a).

1.1.1 Heart transplantation

In this section, I outline the various treatment options available for patients with advanced heart failure with a particular focus on heart transplantation. Often heart failure can be successfully managed with medications, these include diuretics, ACE inhibitors and beta-blockers (NICE, 2010). In addition, there are what NICE (2010) refers to as invasive procedures including: cardiac resynchronisation therapy (CRT), implantable cardioverter defibrillators (ICDs), and pacemakers. All three of these are small electronic devices that are implanted under the skin, with wires that feed into the heart. The number of wires depends on the device and its intended function. Pacemakers are used to treat abnormal heart rhythms that may cause the heart to beat too slowly; these devices can improve symptoms of heart failure (British Heart Foundation, 2015b). CRTs are a specialist type of pacemaker that offers biventricular pacing to improve heart rhythms and symptoms of heart failure; it is suitable for patients who have severe heart failure symptoms (American Heart Association, 2015). ICDs may be fitted to patients with advanced heart failure who are thought to be at risk of a life-threatening abnormal heart rhythm, the ICD has the capacity to deliver a defibrillation, or shock, in the event of a dangerous heart rhythm that can protect from cardiac arrest (British Heart Foundation, 2015c).

For the majority of patients these medications and devices are sufficient to manage their heart failure condition. However, there are some patients who fail to respond to optimal medical treatment. For these patients, heart transplantation offers an alternative. The successful development of this treatment took several decades to achieve. The first human heart transplant was conducted in South Africa by Christiaan Bernard in 1967; this patient lived for 18 days. A year later, the first heart transplant was conducted in the UK. Following this, much of the progress in heart transplantation was achieved at Stanford University in the United States (US), under the lead of Dr Norman Shumway. Despite these initial successes, the general enthusiasm for heart transplantation began to wane because of relatively poor outcomes, these were in terms of days or weeks rather than the hoped for months or years. For a time it was feared that rejection may be an

insurmountable problem. As organ transplantation is essentially the implantation of a foreign object into the body, the transplanted organ is immunologically incompatible and the body's autoimmune response will attack it (Rady and Varheijde, 2014). Immunosuppressant medications are needed to manage this bodily response, a lack of adequate immunosuppressants meant that the development of heart transplantation stalled for some time. It was not until the development of new immunosuppressant drugs, in particular cyclosporine, in the 1980s that progress in heart transplantation began to pick up.

For the past three decades, heart transplants have offered the best treatment option for patients with end stage heart disease and limited co-morbidities (Rose et al., 2001). Heart transplantation can be used to treat conditions such as ischaemic heart disease, cardiomyopathy, valvular heart disease and congenital heart disease (Banner et al. 2011). Heart transplantation offers excellent outcomes, including a 50% chance of survival at 10 years (Stehlik et al., 2010), compared to a 50% chance of survival at 1 year for patients with advanced heart failure (Rose et al., 2001). Heart transplantation is a highly complex surgical procedure; as such the number of centres that offer this treatment are limited in order to maintain a high level of clinical skills. Only six UK centres offer heart transplantation: Birmingham, Glasgow, Harefield, Newcastle, Manchester and Papworth. Patients identified as suitable for transplantation are assigned to their nearest centre.

However, the role of heart transplantation in the treatment of heart failure is starting to diminish. This is primarily due to the decline in the number of donor hearts. Over the past decade, particularly in the UK there have been a steady decline in the number of donor hearts available for transplantation (NHS, Blood and Transplant 2015a). Figure 1 depicts the levels of heart transplants conducted from 2005 against registrations on the waiting list, data retrieved from NHS Blood and Transplant (2015a).

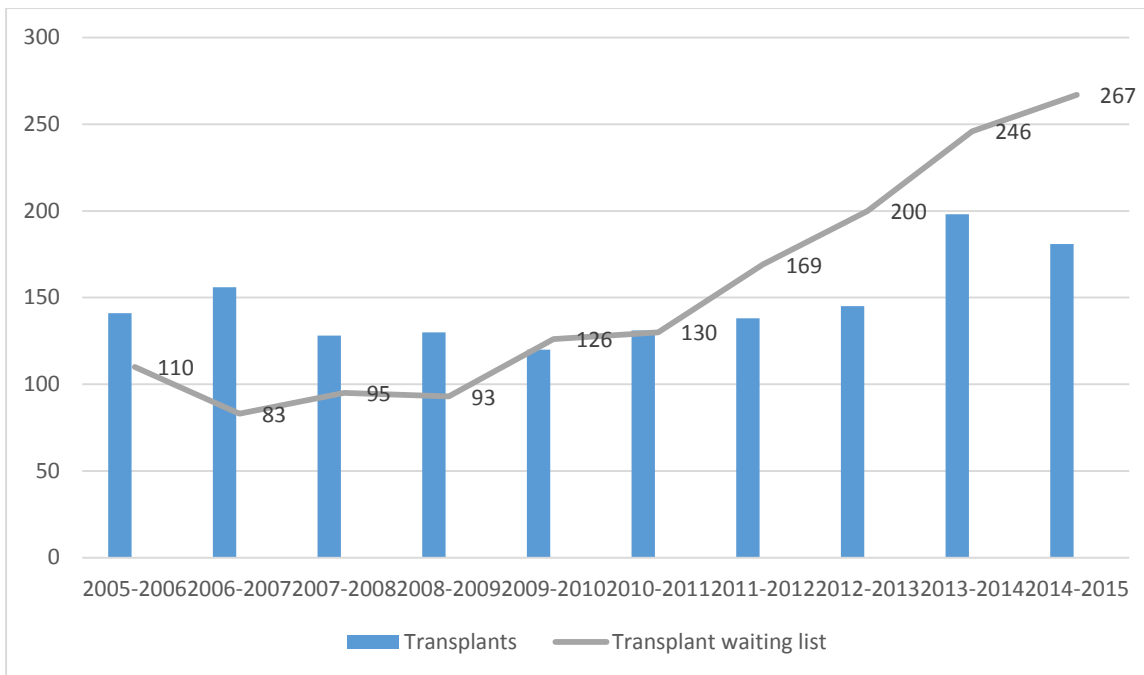


Figure 1: Heart transplant activity 2005-2015 and registrations on waiting list, data retrieved (NHS Blood and Transplant, 2015a)

Reasons for the decline in donor organs have been suggested to include: low numbers of beds in intensive care and improvements in road safety (MacGowan et al. 2011). Heart transplantation is further complicated by the need for the donor to have died of brain stem as opposed to cardiac death. As a result, patients with advanced heart failure are faced with long and uncertain waits for an organ and increasingly mechanical circulatory devices, such as VADs, are being used to support patients with end stage heart failure.

1.2 Ventricular assist devices (VADs)

I turn now to an introduction of VADs; I begin with a history of these devices and their technological evolution. This is followed by an in-depth introduction to the device, and finally a discussion of the commissioning of the devices and their current application within the UK health system.

VADs are mechanical devices, which take over some or all of the pumping function of an individual's heart. They are a type of mechanical circulatory support (MCS). MCS was initially developed to facilitate cardiac surgery. The first use of MCS was in 1952 to support a mitral commissurotomy with left heart bypass (Tang, Oyer and Mallidi, 2009). In 1963, Dr Liotta implanted a device to support a patient with acute cardiogenic shock. Total artificial hearts, another type of MSC, were also developed in parallel to VADs. The first use of an artificial heart as a bridge to transplantation (BTT) was in 1969 by Dr Cooley, the patient survived for three days. Bridge to transplantation is when a device or medication regimen is used to support a patient with

heart failure until such time as a heart transplant may be achieved. In 1982, the first total artificial heart was implanted as a destination therapy, where the device is intended as a long-term treatment. However, the poor outcomes that followed this use of the total artificial heart led to significant controversy. As a result, attention was focused away from artificial hearts and towards VADs. In 1994, the National Heart Lung and Blood Institute issued a call for VAD innovation with a specific focus on increasing the durability of the devices (Tang, Oyer and Mallidi, 2009). Over the two decades following this call the use of VADs has increased exponentially.

1.2.1 Current VADs

Since their first development in the 1960s, VADs have undergone constant development. I now introduce several incarnations of the VAD, including those currently being utilised as a treatment in the UK.

The National Heart, Lung and Blood Institute (2012) distinguish between two types of VAD: transcutaneous devices, for example the Berlin Heart®, and implantable VADs. In the transcutaneous VADs², both the pump and power source are located outside of the individual's body. Whereas, in an implantable VAD the pump is located inside of the patient's body whilst the power source remains outside. The latter type of device is significantly smaller and less cumbersome than the former. Figures 2 and 3 depict a transcutaneous style of device; this is evidently a substantial piece of medical equipment that imposes a high degree of restriction on recipients' independence and mobility. Transcutaneous style VADs are only generally used for short-term support, and in the UK are more commonly fitted to paediatric patients than adults. Individuals fitted with extracorporeal devices are confined to the hospital, for the duration they are on VAD support.

² Transcutaneous VADs are also referred to as extracorporeal and paracorporeal VADs.

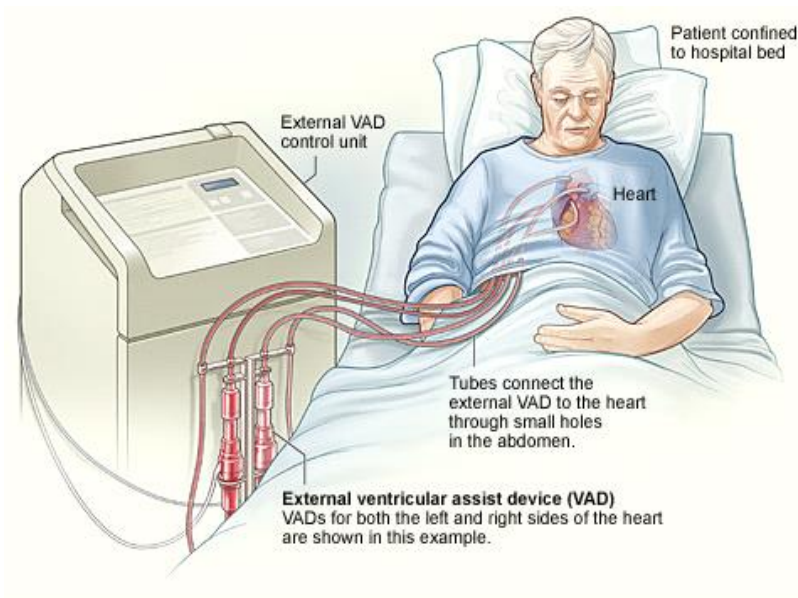


Figure 2: Transcutaneous VAD (National Heart, Lung and Blood Institute, 2012)



Figure 3: Berlin Heart EXCOR® adult torso (BerlinHeart, 2015)

Figure 4 depicts an implantable VAD, similar to those fitted to the respondents in this study. Whilst this device is also comprised of both internal and external components, the external components are much less cumbersome than in a transcutaneous VAD. Most patients fitted with these devices are able to return home, and maintain a high level of independence. From herein the VADs described in this thesis refers to the implantable style of VADs depicted in figure 4 unless explicitly stated otherwise.

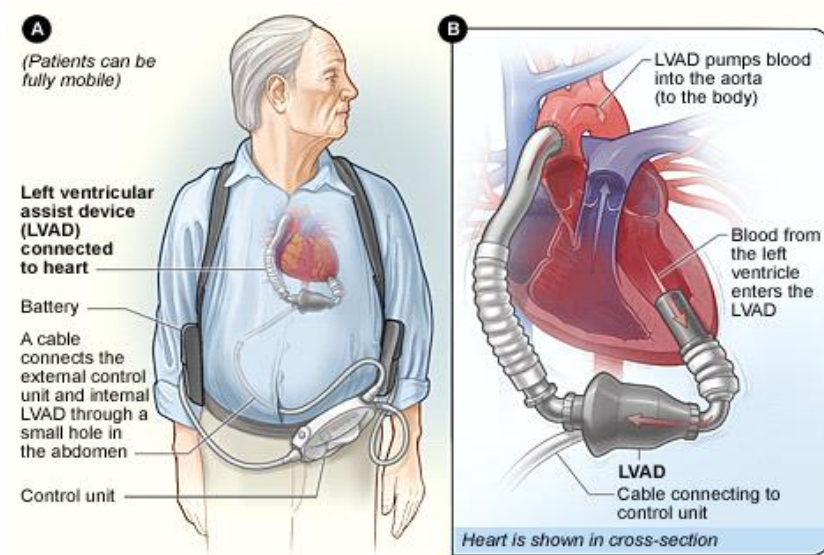


Figure 4: Implantable style VAD (National Heart, Lung and Blood Institute, 2012)

There has been rapid development in VAD technologies over the past decade that has led to a great expansion in the use of the devices (Emin et al. 2013). Thus far, there have been three main incarnations of the implantable VAD; these are commonly referred to as first, second and third generation devices. The first generation of VADs used pulsatile displacement pumps and were prone to failure from bearing or internal valve wear. Second generation devices were non-pulsatile, providing a continuous flow of blood, these devices used rotary pumps with axial flow. Second generation devices had several advantages over first generation, including a smaller size, meaning implantation is simpler and there is a lower risk of infection. Third generation VADs are centrifugal continuous flow pumps, they comprise of an impeller or rotor suspended in the path of blood flow that uses magnetic or hydrodynamic levitation, this design has no contacted bearings meaning there is less wear and tear (Alba and Delgado, 2009).

The majority of participants in this study were fitted with third generation devices; as such it is these device which I will now discuss in further detail. Third generation VADs, like the HeartWare® HVAD® comprise of both internal and external components. The internal components include a pump that is fitted to the patient's heart; an example of the pump is shown in figure 5.



Figure 5: HVAD® pump (HeartWare®, 2015a)

Implantation of the VAD is a major surgical operation requiring open-heart surgery (British Heart Foundation, 2015d). The pump of the VAD is implanted into the heart, usually to the left ventricle. One end of the pump is attached to the ventricle and the other to the aorta. The patient's blood flows from the ventricle into the aorta, whence the device pumps the blood out to the rest of the body (ibid.). Positioning of the pump in the heart is shown in figure 6. VADs can also be fitted with right heart ventricle or to both ventricles which is known as biventricular support.

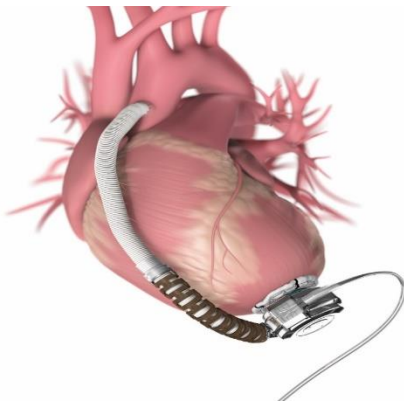


Figure 6: Implanted HVAD® pump (HeartWare®, 2015a)

The external components of the device comprise of a controller and power source. The controller is a small external computer. The controller manages the flow of the pump, it also communicates information about how the device is working, and has the capacity to produce textual alerts and alarms in the event of any problems with the device (HeartWare®, 2015b). The VAD must be connected to a power source at all times, this can either be specialised battery packs or mains electricity supply. Figure 7 shows the controller, batteries and specialised bag for a HeartWare®

VAD system. Patients carry the external peripherals of the VAD, the controller and battery packs, in this specialised bag. Although, many patients opt instead to use bags of their own choosing, this is discussed in greater detail in Chapter 7.



Figure 7: HeartWare® ventricular assist system (HeartWare®, 2014)

The external and internal components of the device are connected by a percutaneous lead known as the driveline. This usually exits the patient's body around their waist; however positioning may vary for individual patients and recurring infection may require the site to be relocated. At the point where the driveline exits the body, the patient has a wound. This must be cleaned and dressed on a regular basis. In addition, the patients use a Hollister clip; this is a dressing with a clip that acts as an anchor to hold the driveline in place. The purpose of this clip is to reduce any pulling or tension on the exit wound if the driveline were to become caught on something. Figure 8 depicts an adult male torso with an implantable VAD in situ, showing positioning of exit wound.



Figure 8: Adult torso with implantable VAD in situ (Newcastle Upon Tyne Hospitals NHS Foundation Trust, 2015)

1.3 Living with a VAD

As the implantation of the VAD requires a major, open-heart surgery there is a lengthy rehabilitation period. This typically involves around a week in an intensive care unit, followed by a couple of weeks in a high dependency unit. However, length of recovery can differ significantly between patients depending on their condition prior to surgery (National Heart, Lung and Blood Institute, 2012).

Implantable VADs, unlike transcutaneous devices, allow the patient to manage their condition at home. Following a suitable period of rehabilitation, patients are discharged home and henceforth they take responsibility for day-to-day management of the device themselves, usually with the aid of a partner or caregiver. Management of the device involves several responsibilities. Kato, Jaarsma and Ben-Gal (2014) have categorised these responsibilities into three levels of self-care: self-care maintenance, self-care monitoring and self-care management. Self-care for the device, involves maintaining a constant power source, cleaning the exit wound and changing dressings several times a week, managing medications, and regular checking and recording of International Normalized Ratio (INR). INR levels check the coagulation of the blood; VAD patients must regularly report this recording to a member of their clinical team so anticoagulation medications can be managed. Thrombosis and bleeding are major complications of the VAD and clinicians must strike the difficult balance between pro and anticoagulation (Felix et al. 2012). Patients must also maintain a healthy life style following implantation. This includes a steady and healthy weight as obesity has been linked to a high likelihood of developing driveline infections (Raymond et al. 2010).

Patients must also have regular check-ups to monitor the device and their condition. Due to the relative novelty of VADs, patients must return to the specialist implanting centre for these check-ups. This activity in itself can impart a large burden on patients' lives. Currently VAD implantation is tied to heart transplantation services, so there are only six centres nationally who routinely deal with the devices. As such, patients are widely geographically dispersed and may have to travel several hundred miles to attend clinic appointments.

There are a number of serious complications that can arise during VAD support. These include bleeding and thrombosis, as mentioned above, as well as stroke, infection and device malfunction (Givertz, 2011). Although improvements in VAD technologies, in particular the introduction of non-pulsatile device, have reduced the chances of some complications these have not been totally eliminated. Indeed, strokes are suggested to be equally common amongst those who have received pulsatile and continuous flow devices (Stewart and Givertz, 2012). Causes of death amongst VAD recipients include worsening heart failure, device failure, sepsis, infection or multi-organ failure (Dans and Garcia, 2015). The most common causes of death are central nervous system or infective events (Emin et al. 2013).

1.4 Current commissioning of VADs

There are some key differences in how the VAD is utilised in different countries. Presently, the UK commissioning body has only approved VADs to be offered as a BTT, or myocardial recovery (NHS commissioning board, 2013). BTT is the practice of fitting the device to patients eligible for heart transplantation thought too weak to survive until a donor heart becomes available. Although in practice, the device is also used as a bridge to decision (Özalp et al. 2014). When used as a bridge to myocardial recovery, the VAD is used to take the strain off the heart; this can potentially allow the heart to recover sufficiently for the device to be later removed. In the US and mainland Europe VADs are also used as a long-term therapy known as destination therapy (DT). In the US, in particular DT is increasing in popularity, it now accounts for a large proportion of all those fitted with VADs, currently over 40% of the VADs being implanted are for DT (Kirklin et al. 2014). There are also key differences in transplantation rates in those BTT between UK and the US. 37% of patients BTT, listed on the US INTERMACS registry, had received a transplant within a year (Kirklin et al. 2014), whereas four years outcomes for a UK sample indicated that only 13% had received a transplant (Özalp et al. 2014). The use of VADs in the UK is likely to change in the near future. There is suggestion that due to the low number of donor hearts from transplantation the use of VADs should be increased in the UK to include DT (MacGowan et al. 2015). Indeed, DT has recently been added to NICE recommendations (NICE, 2015). As a result of these changes, the

number of individuals on VAD support is likely to increase in the near future. As such, it will become increasingly important to understand the impact of these devices on recipients. This leads me to the aims and objectives of this PhD project.

The present study is focused on the experience of those BTT patients with a VAD. Ultimately, there are three potential outcomes of BTT: transplantation, explantation or death with the device in place. Explantation, following myocardial recovery is a rare outcome, less than 4% of a UK sample achieved this in a review of four-year outcomes of third generation devices (Özalp et al. 2014). Probability of a patient BTT receiving a heart transplant is declining due to decreases in the number of donors (Emin et al. 2013). Further, improved survival rates with the VAD are increasing the length of time that patients are sustained with the device; the longest a patient has been supported with the device in the UK is now over six years (ibid.).

1.5 Aims and Objectives

This study is a phenomenological investigation of the experience of VAD patients. Phenomenology focuses on human experience as a topic in its own right (Langdrige, 2007).

The main aim of this study is to understand the essence of what it means to 'Be' a VAD recipient.

The objectives of the study are as follows:

1. To further the understanding of the day-to-day realities of living with a VAD.
2. To explore the impact of the VAD on recipients' bodies and identities.
3. To explore the extent to which the VAD can be adapted into everyday life.
4. To explore the impact of the VAD on social interactions and communities.

1.6 Structure of the thesis

The central tenet of my thesis is that the experience of 'Being' a VAD recipient is liminal existence (Turner, 1969). Life is placed on hold whilst living with the device. This introductory chapter has provided some background information that situates this research project in the context of the use of VADs in the UK. The next chapter provides a review of the available qualitative and quantitative literature exploring the impacts and outcomes of VAD support. I outline the gaps in our knowledge of this phenomenon. In this second chapter, I also present some other literature that is of relevance to the concepts discussed in the thesis. This includes a brief review of more general literature exploring the impact of chronic illness and literature from the field of science and technologies studies that explores the impact of technology on the body and identity.

Chapter 3 introduces interpretive phenomenology as the methodological underpinning of the study. In this chapter, I discuss the origins of phenomenology and present the contrasting approaches of Husserlian and Heideggerian phenomenology. This chapter demonstrates the usefulness of interpretive phenomenology as an approach for health research and its appropriateness for this study. Chapter 4 introduces the practical application of interpretive phenomenology in the undertaking of the research. I document the specific research process and outline the recruitment process in detail. I describe the study sample, before introducing each participant individually. This chapter also introduces some of the ethical considerations of the project, and how these were minimised and managed.

Chapters 5 to 9 present the empirical findings of my study. The data collected from respondents has informed the structure of these chapters. In Chapter 5, the first of my empirical chapters, I focus on the experience of receiving a VAD, exploring how individuals respond to the offer of the device and the process of getting it implanted. Chapter 6 moves on to explore the way that VAD recipients manage the device in their day-to-day lives. This includes a discussion of the materiality of the VAD and its impact on the individuals' life. I introduce some theories that may help to explain the impact of merging one's body with technology in the way that is required by the device. I also discuss the potential of VAD recipients integrating the device into their bodies and identities. Chapter 7 builds on the exploration of the materiality of the VAD, this time focusing on the impact of the device on the individuals' identity. This includes a discussion of how the presence of the VAD may influence the manner by which others orientate to the individual; these ideas are discussed in reference to the sociological stigma literature. Sociological ideas of passing and covering are discussed in terms of their ability to help us understand how VAD recipients manage the device. Chapter 8 discusses the impact of the VAD on community and social relations. I suggest that the VAD may have a negative impact on the recipients existing social relations but may also afford the development of new and valued relationships within the VAD community. I discuss some of the benefits that VAD recipients may derive from these interactions in reference to social comparison literature. Chapter 9, the final empirical chapter focuses on the central tenet of the thesis, that the experience of 'Being' a VAD recipient is in essence liminal. This chapter presents some examples of where this liminality is evident across the trajectory of living with a VAD, from receipt of the device to becoming an established VAD recipient.

Chapter 10 presents the impact and implications of the thesis. In this discussion chapter, I outline the findings of my study in reference to previous research in this area. I have structured the discussion chapter to outline the implications of the study for different audiences. These audiences

are as follows: the VAD recipients themselves, clinicians, and finally social science. While obviously linked, I believe the findings of this study have different implications for each of these groups. The main implication for VAD recipients is that the experience of living with the device is liminal. I suggest that the presentation of the device as a temporary treatment is likely to be a strong factor in the development of this liminality, that many recipients are focused upon achieving a heart transplant in the future rather than developing a life around the device. The main implication for a clinical audience is the possible need to reevaluate the manner in which the VAD is utilised as a treatment in the UK, the presentation of the device as a temporary treatment does not appear fit the experience of living with the device for the majority of participants in this study. In the discussion chapter, I also outline areas of interest that have arisen from the present study that warrant further attention. In particular, I focus on the need for a better understanding of how, and the extent to which, palliative care is integrated into the care of patients fitted with VADs.

This thesis concludes in Chapter 11, with a final summary of the key findings of the study and the important implications for clinical practice.

2

Literature Review

Chapter 2. Literature Review

2.1 Introduction

The purpose of this second chapter of the thesis is to introduce some of the literature relevant to the experience of living with a VAD. Although this PhD project is in essence a sociological piece of work, literature from a range of disciplines has influenced my thinking and interpretation of findings throughout the undertaking of the project; this is reflected in the literature presented in this chapter.

I begin this section of the thesis with an overview of relevant literature that explores the experience of individuals' living with a chronic illness. I follow this with an introduction to science and technology literature that has explored the impact of technology on the body. I conclude this chapter with a discussion of the existing literature pertaining to VADs. Firstly, I present an overview of contemporary clinical outcomes and quantitative literature that has explored effects of VAD support on patients. Attention is then turned to the primary focus of this review, the qualitative literature exploring the experience of VAD recipients. I present an overview of some of the key findings of existing literature and discuss what these findings are able to tell us about the experience of living with a VAD. I conclude the chapter with a discussion of the gaps in the existing literature that I hope this project will address.

2.2 Chronic illness literature

In this first section of the literature review, I turn to literature that has explored the impact of chronic illness. As this thesis is at its core a sociological investigation of the experience of living with a VAD, I have primarily focused on key theories from medical sociology that may aid us in understanding this phenomenon. This section does not pertain to be a comprehensive review of this literature; this was not achievable within the confines of this PhD project. However, it provides an overview, with the purpose of highlighting key concepts that will aid in the understanding of issues discussed later in the thesis.

2.2.1 Chronic illness as a biographical disruption

Medical sociology has investigated the body and illness beyond purely physical or biological terms. It has sought to take into account the impact of environmental, cultural, social and political influences on the body. One of the key sociological theories of chronic illness is Michael Bury's (1982) theory of biographical disruption. Bury (1982) developed his theory in response to a perceived neglect of the impact of chronic illness by medical sociologists; he felt that too much

focus was placed on the experience of acute illness. The theory of biographical disruption suggests that the development of a chronic illness is a 'critical situation', a term borrowed from Giddens (1979). Bury (1982) compared the onset of chronic illness to the onset of war, both events undermine and make visible aspects of one's selfhood and existence that were previously in the background, and both bring the possibility of death to the forethought. The development of a chronic illness creates a situation where meanings are at risk (Bury, 1991).

The theory of biographical disruption does however have detractors; this is mainly focused on the generalisability of the theory. The idea that chronic illness is experienced as a disruption to normal life requires there to be a universally held conception of what is normal (Reeve et al. 2010). However, as this is does not necessarily hold true, and commentators have warned against the assumption that biographical disruption holds for everyone (Faircloth et al. 2004). Bury's (1982) conception appears to assume that chronic illness always enters a life hitherto untouched by chronic illness. However, from our own experiences, we know this is rarely the case. Previous experiences are likely to influence how we orientate to an illness. Indeed, this has been illustrated amongst women diagnosed with HIV; the diagnosis of the condition may not be experienced as the most disruptive event in an individual's life if they have previously experienced disruptive events such as abuse or loss of children (Ciambrone, 2001).

However, Bury accounted for these differences suggesting that the same illness may be considered as a normal feature or abnormal feature of a sufferer's life (Anderson and Bury, 1988). They suggested that there are two types of meaning involved in chronic illness. The first meaning relates to the consequences of the chronic illness for the individual. Whereas, the second meaning relates to the significance of the illness for the individual. The significance of an illness can impact on the individual's regard for themselves and how they believe others will perceive them (ibid.). Anderson and Bury (1988) illustrate this using the example of osteoarthritis; development of this condition may be considered a normal feature of life if it has been biographically anticipated. Stroke has been used as an example to demonstrate how illness events are contextualised within our lives and life experiences, the event may considered 'not that bad' (Pound, Gompertz, and Ebrahim, 1988). Further Faircloth et al. (2004) suggest that stroke survivors may normalise the event and experience it as a natural and expected part of old age.

Furthermore, concepts of health have also been suggested to differ between socio-economic classes (D'Houtaud and Field, 1984). D'Houtaud and Field show that, in the 1980s, for French persons of high socio-economic class, ideas of health were focused on the ability to participate in a hedonistic life style, whereas lower classes focused on their ability to fulfil their role in society (ibid.).

Several alternatives to biographical disruption have been suggested that take into account these differences. Firstly, Faircloth et al. (2004) suggest the concept of biographical flow may be more appropriate, allowing us to understand the illness as part of an ongoing life. Further, Locock, Ziebland and Dumelow (2009) have suggested biographical abruption, is more appropriate than biographical disruption in certain conditions. They draw on the experiences of motor neurone disease patients. Biographical abruption is used to convey the feeling that for these patients the diagnosis is essentially a death sentence.

2.2.2 Chronic illness and the body and identity

The experience of a chronic illness has been suggested to impart a large impact on the sufferer's self-identity. The chronically ill individual may experience the crumbling away of their former self-image without the subsequent development of new images that are equally valued (Charmaz, 1983). Furthermore, those who are chronically ill may experience frustration stemming from the desire that others recognise they are ill, but the illness is only part of their personhood, not something by which they necessarily wish to be defined. Those suffering from chronic illness may also feel the need to convince others of the legitimacy of their illness, these others may include both medical professionals and family members (ibid.).

Medical sociological models of chronic illness, such as biographical disruption, have been suggested to neglect the role of the body, focusing instead on the cognitive interpretations of illness and the meanings attributed (Kelly and Field, 1996). The importance of the body in chronic illness is suggested to be threefold (Kelly and Field, 1996). Firstly, bodily factors impinge on the self; secondly they provide signals for identity reconstruction; and thirdly they act as limiting factors on social interaction. However, Williams (1996) rejects many of Kelly and Field's (1996) claims about neglect of the body, arguing that many of their suggestions are already present in the chronic illness literature, in the work of Goffman (1963) amongst others. Although, he acknowledges that corporeal matters are often an implicit rather than explicit theme of the research. He proffers body-image as a way of understanding the body, this term highlights the co-dependence of the mind and body and the impossibility of conceiving of them as separate entities (ibid.).

As VADs are a medical technology that makes demands of the recipient in terms of self-care, the implications of the technology on the body are likely to impact on the experience of living with the device. The role of the body is a key factor in this thesis. VADs are mechanical devices that are implanted into patients' bodies in an intimate manner. As such, it is important to consider the

impact on the recipient's body and how this influences the experience of living with the device. The next section of the literature discuss some theories of the body and how it is experienced.

2.3 Experience of the body

The VAD is a medical device that is implanted into the body in an intimate and intrusive manner; it takes over the functioning of what is possibly the most symbolic organ in the body. In this next section, I present some literature that has explored the manner in which we experience our bodies. In this thesis I have adopted a phenomenological approach to the experience of 'Being' a VAD recipient, as such much of this discussion is focused on phenomenological conceptions of the body.

Over the last decade or so there has been a movement to corporealise sociology, to move away from focusing on the body as an object, towards the body as a thinking and doing subject (Howson and Inglis, 2001). This has involved an incorporation of phenomenological lines of thought, in particular the experiential phenomenology of Merleau-Ponty (1945), into sociological conceptions of the body.

Merleau-Ponty (1945) suggested that it is through our bodies that we experience the world. The body is our anchorage in the world and it is through the body that we relate to others. Merleau-Ponty (1945) notes that, whilst human experience is always embodied, the body is seldom a thematic object of our experience; rather it is through our body that we orientate to the world. Further, he suggests that when the body is functioning unproblematically we are only pre-reflectively aware of it; the body disappears because it is not the thematic object of experience, the object of our experience is usually something outside of the body. This pre-reflective bodily self-awareness makes it possible to engage in basic activities such as walking without the need to think about locomotion (Zeiler, 2010). We do not have to think about these skills because they have been incorporated into our bodily schemas (Merleau-Ponty, 1945).

Merleau-Ponty's conception of the body has been further developed by Leder (1990) in his theory of the dys-appearing body. He stated that the natural state of the body as outside of our perception may be disrupted when we encounter illness or pain. Pain may bring the body into the primary focus of our attention, the body dys-appears and becomes apparent in its dysfunction (ibid.). Pain is a manner of being-in-the-world, it reorganises our lived space and time. During times of pain and dysfunction the body stands out to us because its usual state is to be lost in the world. Leder's (1990) concept of dys-appearance is illustrated using the concept of the blind man's stick. The blind man, when first employing the stick experiences it as an external object exerting impacts upon his

hand. However, once he masters the stick he will begin to feel through the experiential field that the stick discloses. The stick becomes part of the 'form' structure of the body.

Like pain, the experience of chronic illness and its accompanying treatments may bring the body back into consciousness. In the following section, I outline some key theories that aim to explain how technology may reshape our bodies and identities.

2.3.1 *Cyborg theories*

In chapters 5 and 6 of this thesis, I explore the impacts of the VAD on the recipient's body and identity. In this section of the literature review, I introduce some theories that may aid our understanding of the impact of merging our bodies with technology in an intimate manner.

Advances in medicine are increasingly challenging the boundaries of the human body. The body is increasingly open to human intervention (Budgeon, 2003), and it is becoming increasingly common for the body to be adapted, supplemented and replaced in the face of illness. Modern biomedical practices appear to view the body as something that can be remoulded without consequences to the embodied self (Mauthner et al. 2014). However, impacts to the self are evident. Medical technologies offer us unprecedented control over the human body, which may compel a crisis over what the body is and what it may become (Jackson, 2002).

Much of the research exploring the impact of technology and the body has originated from the discipline of science and technology studies (STS). STS literature has conceptualised technology as a means of dissolving the boundaries that exist between humans and animals, the physical and non-physical and humans and machines (Haddow et al. 2015). These studies have attempted to explain what it means for the body when we are implanted with a piece of machinery. Mazis (2008) suggests that humans implanted with machinery fall in-between the space of humans and machines. One of the key theories in STS of the body asserts that the mix of humans and technology results in the development of cyborgs. A cyborg is a scientific chimera, which comes into existence when two types of boundaries are simultaneously breached, such human and machine (Williams, 2003). The cyborg is a liminal creature that precipitates a reconsideration of what it means to be human (Klugman, 2001).

The term cyborg was originally developed in the field of medical cybernetics to indicate a fusion of a human or animal with machine. The very first 'cyborg' was a mouse developed as part of an investigation into the feasibility of altering human bodily functions in order to facilitate extra-terrestrial travel (Clynes and Kline 1960; Clynes, 1995). The concept of cyborgs really came to prominence with Donna Haraway's 'Cyborg Manifesto' (1991). She states that:

Cybernetic organism, a hybrid of machine and organism, a creature of social reality as well as of fiction. (ibid.: 150).

Despite the popularity of cyborg theory in STS literature, there is a degree of debate as to what exactly it means to be a cyborg and who qualifies for this title. At one end of the spectrum it is suggested that we are all cyborgs to some extent as modern life is so intertwined with technology, and that, rather than a binary category, cyborgness is a continuum on which we all lie (Featherstone et al. 1995). On the other hand, Chorost (2005) who has written extensively about his own experiences of receiving a cochlear implant suggests that 'cyborg' is a special condition. He differentiates between *fyborgs*, and *cyborgs*. *Fyborgs* or functional cyborgs, are individuals augmented by externally worn equipment, and this concept can be applied to almost all humans. However, cyborgness is the presence of software that makes and carries out if-then-else decisions about the body (Chorost, 2005). Others have suggested that becoming a cyborg is the outcome of a change of existence, that one can no longer be fully human or oneself without mechanical support (Chorost, 2005; Mazis, 2008). Previous literature exploring the impact of other heart technologies suggests that ICD recipients are 'literally cyborgs' as they rely on cybernetic command, control and communication, whereby both the patient and the device are dependent upon infrastructure to function and survive (Bjørn and Markussen, 2013: 15).

Haddow et al. (2015) have explored the idea of being an everyday cyborg; this is a hybrid of a machine and organism. They suggest that previous literature has neglected individuals' willingness to become a cyborg. People may experience ambivalence when confronted with the idea of becoming a cyborg and the incorporation of technology into the body as the technology carries the risk of malfunction. Willingness is contextually dependent, for example, in relation to men receiving biosensors to detect for prostate cancer the technology is accepted over an alternative of cancer.

2.4 Heart transplantation

The current use of VADs as a treatment for heart failure is tied inextricably with heart transplantation. As such, it is important to understand how impacts and outcomes of VAD support compare with transplantation. In this section, I provide a brief overview of findings from qualitative studies that have explored the experience of heart transplantation.

Heart transplantation is a treatment reserved for patients with end stage heart failure who have failed to respond to optimal medical treatment. These patients are, for the most part, critically ill

prior to the transplant, which is a period of time characterised by the presence of death (Flynn et al. 2014). The heart transplant, and the improvements it may confer, is viewed with great hope and anticipation. There is a tendency for the transplant to be viewed as a transition from illness to normality (O'Connor et al. 2009). However, life post-transplantation does not necessarily meet prior expectations, and patients have described feeling responsible for the success or failure of the transplant (Flynn et al. 2014). The first year post-transplantation is suggested to be a period of physical and emotional recovery, and this process of recovery often takes longer than is initially expected (Dew et al. 2002).

The heart as an organ is thought to have a special significance; it appears to hold a special role in our consciousness. Following the first heart transplant conducted by Christiaan Barnard, Mazrui (1968) highlighted the attention that was given to the heart in particular as a symbolic organ. Further, Bound Alberti (2010) highlighted two diverging views of the heart that coexist in our conception of the organ, it is both a mechanical pump but also the seat of emotion. She suggests that the cultural and spiritual origins of the heart as a symbol of affect and the seat of emotion originate from classical ideas of the body and mind. Martyn et al. (2012) have noted the impact of the special status of the heart in medical student's emotional reactions when faced with dissecting a heart for the first time. Heart transplantation is suggested to bring about greater self-reflection than transplantation of other organs (Svenaesus, 2011). Heart transplant recipients have described the transplanted organ as an intrusion into their sense of self, which may cause identity disruption (Mauthner et al. 2014). Difficulties in adapting psychologically to the transplanted heart have been related to this view of the organ as the container of spiritual and emotional life (Inspector, Kutz and David, 2004). In order to counter these difficulties recipients are encouraged to view the heart transplant mechanistically, as a reusable pump or spare part (Shildrick et al. 2009). Further, findings suggest that heart transplantation raises issues about embodiment and identity. Several research studies reported that transplant recipients experience concerns about taking on characteristics of the donor (Bunzel et al. 1992; Sanner, 2003).

Heart transplantation as a treatment for advanced heart failure carries many potential challenges for the recipient in terms of disruption to one's body and identity. Mechanistic conceptions of replacement parts do not appear useful for understanding the experience of these patients. These studies that outline the experience of heart transplantation are essential for understanding the findings of this thesis in the context of VADs position as a treatment for advanced heart failure.

2.5 VAD research: Clinical outcomes

I turn now to previous VAD research. I begin this section with an overview of some the current clinical outcomes reported for the VADs. This quantitative research base is presented with the intention of providing background and context for what follows in both this chapter and the rest of the thesis. The purpose of this thesis is not to debate the clinical efficacy of VADs, but rather to explore the impact of these devices on recipients and to uncover the experience of 'Being' a VAD recipient. As such, this section does not pertain to be an exhaustive account of clinical outcomes.

Cardiologists in the United States (US) have developed the Interagency Registry for Mechanically Assisted Circulatory Support (INTERMACS), this is a National Heart Lung and Blood Institute (NHLBI) sponsored database that tracks the outcomes of all long-term VAD patients. The sixth annual report, which now includes over 10,000 patients with a VAD, has found that survival with continuous flow devices is 80% at 1 year and 70% at 2 years (Kirklin et al. 2014). Similarly, the UK Cardiothoracic Transplant Audit (UKCTA) has established its own Mechanical Circulatory Support Registry; this collects data from the use of all VAD devices in the UK (Emin et al. 2013). Recent reports from this registry have demonstrated how survival rates have increased as VAD technologies have improved. Amongst recipients of first generation devices, only 50% were alive at 1 year, compared to 68.1% with a second-generation device and 76.9% with a third generation device (Emin et al. 2013).

VADs are only currently commissioned as a bridge to transplantation in the UK (NHS commissioning board, 2013). However, as discussed in the introduction to the thesis, there are currently low levels of transplantation activity in the UK (NHS Blood and Transplant, 2015a). As such, many patients fitted with VAD as a BTT will never receive a transplant. A study from a UK implanting centre found that only 14% of patients fitted with a VAD for BTT had received a heart transplant within a four-year study period (Özalp et al. 2014). Amongst those who are lucky enough to receive a heart transplant, current research indicates mostly positive outcomes. Time spent on VAD support does not appear to compromise post-transplant outcomes (Ghafourian et al. 2015). Infection during VAD support does not appear to affect the likelihood of the patient receiving a transplant or survival post-transplantation (Tong et al. 2015). Although a comparison of intra and extra corporeal VADs indicated that whilst the former did not impact on post-transplant outcomes the latter did (Alba et al. 2011). Furthermore, research has suggested that VADs may induce allosensitization, which may lead to higher mortality rates post-transplantation due to increases in antibody mediated rejection (Kidambi, Mohamedali and Bhat, 2015).

In addition to post-transplant outcomes, quantitative research has explored impacts of VAD support. Several studies have indicated that VAD implantation has a negative impact on sexual functioning (Eckman et al. 2013; Hasin et al. 2014; Merle et al. 2015). A Major focus of quantitative studies is on quality of life (QOL) outcomes (Wray and Banner, 2007). MacIver and Ross (2012) have found that VAD patients experience improvements to QOL 3 months after implantation, although women and older recipients take longer to achieve these outcomes. However, they also suggest patients may also retain a level of distress, of which the uncertainty of their situation and fear of device failure were key features. QOL scores indicate that those on implantable VAD support fare better than those on extracorporeal support (Kato et al. 2015). Attempts have been made to develop a QOL measure that is specific to VAD recipients (Sandau et al. 2014). Overall, QOL is described as the ability to be independent or 'normal', it was defined as 'being well enough to do and enjoy day-to-day activities that are important to me' (32).

Shapiro, Levin and Mehmet (1996) found that psychiatric problems such as depression and adjustment disorders were common amongst VAD recipients. However, it should be noted this was most common for those who experienced medical complications. Additionally, VAD technologies have improved significantly since the first generation devices used in this study and patients are no longer faced with the same degree of complications. Bruce et al.'s (2014) more recent analysis of psychosocial outcomes indicates three variables that are associated with VAD outcomes: depression, functional status and self-care. Depression and anxiety scores appear to reduce following implantation and are stable for up to a year (Reynard et al. 2014).

Attempts have been made to predict VAD patient outcomes, it is suggested that these are likely to be similar to those identified as predictors of transplantation outcomes (Grogan et al. 2015). Maltby et al. (2014) has applied the psychosocial assessment of candidates for transplantation (PACT) to VAD patients. They found that revising the scale to emphasise device understanding, social support, psychological health and lifestyle factors was successful in predicting VAD outcomes. This suggests there may be a role for such a tool in the selection of patients, which would allow the identification of those who will fare best with the device.

However, there are questions relating to the ability of such research to uncover fully the experience of VAD support. QOL scores may not be sufficient to uncover the distress experienced by these patients (MacIver and Ross, 2012; Modica et al. 2015). Whilst the studies presented above are useful in establishing the clinical effectiveness of VADs as a treatment and provide insight into the psychosocial impacts of the device, they tell us little about the day-to-day realities of living with the

device. If we are to understand what it means to ‘Be’ a VAD recipient, we need to look to the impacts of the device in patients’ everyday lives.

2.6 VAD research: Qualitative studies

The final set of the literature that I discuss in this chapter is the existing qualitative literature exploring the impact of living with a VAD. As will become apparent from the discussion below there is limited literature available that explores this phenomenon. The paucity of literature is a reflection of the relatively rapid development of these devices and their adoption into the treatment of advanced heart failure. Whilst the focus of the present study is on the experience of the VAD recipient, in this section I also present research that explores the experiences of caregivers of VAD recipients. I believe that the experiences of patients and caregivers are inextricably linked, and given the limited prior research, I do not believe it would be beneficial to exclude the caregiver literature from this discussion. In this section, I present the key findings of previous qualitative studies, this to provide an overview of what is currently known about the experience of living with a VAD. Table 1 provides a brief summary of the existing qualitative VAD literature.

Table 1: Summary of previous Qualitative VAD literature

Author	Country	BTT or DT	Participants	Methods & Methodology	Findings
Blumenthal-Barby et al. (2015)	USA	DT	45 patients and caregivers	In-depth structured interviews	Themes: Decision making quick and reflexive, defer to clinicians opinions, not making a real choice, desire to meet other patients, lack of clarity regarding chances of transplant.
Bruce et al. 2015	USA	BTT and DT	21 VAD decliners	Semi-structured interviews	Reasons for decline temporal. Initial refusal reflexive. Patients change mind following worsening of symptoms. Concerns about impacts on mobility, distrust of technology and ability to achieve HTx.
Casida (2005)	Canada	BTT	3 caregivers	Semi-structured interviews Interpretive phenomenology	3 key themes: emerged-emotional distress, determination, and optimism: a new lease on life.
Casida et al. (2011)	USA	BTT and DT	9 VAD recipients	Semi-structured interviews, Van Manen's phenomenology	Overarching theme that adjustment takes time.

Chapman et al. 2007	UK	BTT	6 patients	Semi-structured interviews	Two main themes: Body and self, and trust. Body and self: shock, restrictions, scarring and infection Trust: Keeping me alive, device failure and confidence
Egerod and Overgaard (2012)	Demark	Not specified	7 Relatives of VAD recipients	1 paired interview (n=2) 1 group interview (n=5) Grounded theory	Importance of support and self-preservation for relatives of VAD recipients.
Hallas et al. (2009)	UK	BTT	4 VAD in situ, 4 explant, 3 post-transplant	Semi-structured interviews	Control was the core category, subcategories of normality, uncertainty, emotional state. Identity of illness and impact of device were key for those with VADs in situ. Independence key post-transplant.
Kaan et al. (2010)	Canada	DT	13 Caregivers of 9 patients	Phenomenological framework Focus groups	Four themes: anxiety, loss, burden and coping

Kirkpatrick et al. (2015)	USA	DT	42 caregivers	Mixed methods Grounded theory analysis of responses to open ended questions	Caregiver being able to handle heavy burden prerequisite of implantation, critical role in decision making, preparation, social and psychological burden, impact on freedom, and value of psychological and social support.
Kitko et al. (2013)	USA	DT	10 caregivers	Semi-structured interviews	Ability to adapt to caregiving role. Adaption occurred through three timeframes: caring for spouse with heart failure, decision to implant VAD, caring for spouse with VAD.
Kostick and Blumenthal-Barby (2015)	USA	DT	1 patient and caregiver	Case study	Complications of living with the VAD, suspension in limbo.

Magid et al. (2015)	NA	BTT and DT	8 articles about caregivers	Meta-analysis of caregiving articles	Highlight caregiving as a longitudinal process, broken into three stages. Early stage (before LVAD to procedure): no option, emotional rollercoaster Middle stage (post-implant): fragility of patient, need for adaptation Late stage: BTT or DT brings into focus what is important for caregiver.
Marcuccilli and Casida (2011)	USA	DT	5 caregivers of VAD recipients	Hermeneutic phenomenology	Themes: Caregiving is a 24/7 responsibility, coping strategies, satisfaction.
McIlvennan et al. (2014)	USA	DT	15 VAD recipients 7 Decliners	In-depth semi-structured interviews	Dichotomy between decision making process, automatic and reflective decision makers. Automatic were characterised by a strong fear of dying. Reflective engaged in a balanced weighing of risks.

McIlvennan et al. (2015)	USA	DT	17 caregivers of patients considering DT VAD	In-depth semi-structured interviews	Key themes: Stark decision- tension between hope and reality. Challenging decision process. Downstream decision- tension between gratitude and burden.
Modica et al. (2015)	Italy	BTT and DT	26 VAD recipients	Open ended interviews	Impacts of VAD acceptance included: type of device, experience of disease, nature of device, doctor patient relationship, opportunities for sharing experience, patient's psychological characteristics.
Ottenberg et al. (2014)	USA	DT	12 patients	In-depth interviews Thematic analysis	Six key themes: Preparedness planning, new lease on life, optimising support networks, systemic limitations, reflections on time, communication matters.

Overgaard, Kjeldgaard, and Egerod (2011)	Denmark	BTT	10 patients	Semi-structured in-depth interviews	Structured chronologically: transition to illness, transition to LVAD, life with LVAD and life after transplantation. Experiences of life with VAD distinct for different age groups, those with vocational security more likely to resume work and normal life.
Sandau et al. (2014)	USA	BTT and DT	11 patients	Semi-structured interviews Grounded theory	Developed conceptual definition of QOL for VAD patients. Five key domains: physical, emotional, social, cognitive and spiritual. QOL is 'being well enough to do and enjoy day-to-day activities that are important to me' (32)
Zambroski et al. (2009)	USA	BTT and DT	6 patients	Semi-structured interviews	Four key themes: Facing the unknown, feeling confined, living with fear, and hope for the future.

2.6.1 VAD as an object of fear and anxiety

One of the key findings from previous studies is that the receipt of a VAD is a source of fear and anxiety (Kaan, 2010, Zambroski et al., 2009). This fear can persist through all stages of the VAD experience (Kaan, 2010), and can encompass the entirety of the patients' existence (Zambroski et al., 2009).

Fear and anxiety appears to be particularly acute in the initial reactions to the device from both patients' and caregivers. The offer of the VAD could precipitate an awareness of the seriousness of the patients illness and their closeness to death (Overgaard et al., 2011). The VAD could impart changes to the recipients' bodies and lives (Chapman et al. 2007), and for many was an assault to their sense of self and identity (Casida et al., 2011).

Several studies have explored the decision-making process involved in having a device implanted. McIlvennan et al. (2014) differentiated between automatic and reflective decision makers. Automatic decision makers did not perceive they had a choice about whether to have the VAD, whereas reflective decision makers viewed death as an option which was worthy of consideration. In another study, individuals who initially declined the device but changed their mind described the turning point of their decision being the realisation of how sick they were and that symptoms had become so extreme they severely impacted on day-to-day life (Bruce et al. 2015). Other studies have indicated that the decision-making process is heavily reliant on clinicians (Blumenthal-Barby et al. 2015). Furthermore, it is not always the patients themselves who make the decision to have the device implanted this may fall to caregivers. Caregivers who have made the decision report feeling that they had no choice but to consent to the device (Kitko et al. 2013), and making the decision increased the amount of anxiety the caregivers experienced (Kaan, 2010).

Studies suggests that life with the device is characterised by a fear of the unknown (Zambroski et al. 2009). An important aspect of the fear and uncertainty experienced by VAD patients is the reliability of the device and the possibility that it may fail (Chapman et al. 2007; Zambroski et al. 2009). It appears that over time, patients can become reliant on the device, however this reliance can also cause fear and anxiety in its own right. Patients may come to see the device as a comfort blanket and experience discomfort at the possibility of its removal (Chapman et al. 2007).

2.6.2 VAD as a disruption to identity

It has been suggested that receipt of a VAD can result in a loss of previously valued identities. One aspect of identity that is disrupted by the patients' illness and the implantation of the

VAD is their ability to work. Work is an important aspect of individuals' identity that may be lost following the implantation of the VAD (Casida et al., 2011). Overgaard et al. (2011) mapped the impacts of the VAD against the patient's stage of life. They suggested that the impact of the loss of working identities differed depending on the individual's stage of life. For young patients at the beginning of their career, the VAD led to a re-evaluation of options and precipitated the need to look for alternatives. Older adults viewed work as an important facet of their identity and were reluctant to give it up (ibid.).

A major facet of the experience of VAD patients is a lack of independence and an experience of confinement (Hallas et al. 2009; Kaan, 2010; Zambroski et al., 2009). Several studies have compared the experience of living with the VAD to being in prison, the individual has no control over their own lives and is reliant on others to help with basic day-to-day tasks (Casida et al., 2011; Zambroski et al., 2009). Loss of independence, and becoming dependent upon a caregiver for everyday tasks was one of the most difficult aspects of the experience. Further, patients' desire for independence could be a source of disagreement between the patient and their caregiver (Hallas et al. 2009, Marcuccilli and Casida, 2011). Whilst caregivers acknowledged the patients' need for independence, this was difficult to balance with their desire to do a good job in their roles as caregiver (Marcuccilli and Casida, 2011).

The VAD also appears to carry interpersonal impacts, influencing how others respond to the recipient. Marcuccilli et al. (2011) investigated the impacts of the VAD on the recipients' personal relationships, focusing specifically on issues concerning sex and intimacy. Single patients were found to express concerns about the impact of the VAD on their ability to form intimate relationships fearing that the VAD would make them less appealing to potential new partners (ibid.). As such, the VAD appears to disrupt the patients' identity as a sexual being and their ability to engage in interpersonal relationships.

2.6.3 Acceptance and normalisation of life with the VAD

Much of the previous literature exploring the experience of VAD patients has highlighted the receipt of the VAD as a disruption to the patients' sense of normality. Adjusting to the VAD and the limitations it imposes can be a difficult process (Casida et al. 2011). Often patients appear to have mixed feelings towards the device, the life offered by the VAD is limited, however it appears this is ultimately accepted (Chapman et al. 2007; Overgaard et al. 2011).

Control has been highlighted as a key feature of experience for VAD recipients, patients appear to try to normalise their experiences (Hallas et al. (2009). The importance of feeling normal has been highlighted as a way of getting control over living with the device

(Marcuccilli and Casida, 2011). Normality is a safe and desirable state that patients sought to achieve (ibid.). However, life offered by the VAD is a new normal, involving significant changes to all areas of life (Sandau et al. 2014). Development of a new normality around the VAD requires the patient to adjust their expectations about what is normal in everyday life and the development of new routines that deal with the limitations and restrictions of the device (Hallas et al. 2009; Ottenberg et al. 2014). Caregivers appear to recognise that patients' desire for a normal life and try to incorporate this into their role (Marcuccilli and Casida, 2011). However, caregivers themselves may also experience a disruption to their sense of normality, yet many are able to accept this and move on with their lives (Casida, 2005). I will discuss the impacts on caregivers in greater detail in the following section.

There appear to be mixed findings regarding patients' perceptions of life with the device. On the one hand, patients appear to become accustomed to the device. Indeed, aspects of the device initially experienced as an annoyance, such as the whirring noise of the pump, could come to be seen as a comfort blanket (Chapman, 2007). The noise of the VAD whilst initially experienced as an irritation becomes tangible evidence that the device was keeping them alive and the idea of losing this comfort blanket can be a source of distress (ibid.). Contrastingly, other accounts suggest life with the device is problematic. Caretaking of the VAD imparts large demands on the patient and caregivers, and this can lead to the perception that time was no longer their own it becomes centred around the demands of the device (Ottenberg et al. 2014). Further, life with the device has been conceptualised as being on standby or in limbo (Kostick and Blumenthal-Barby, 2015; Overgaard, Kjeldgaard and Egerod, 2011). This indicates that VAD recipients feel unable to fully develop a new life around the VAD.

2.6.4 Caregivers experiences

A substantial proportion of the existing VAD literature has focused specifically on the experience of caregivers of VAD recipients. Like patients, caregivers experience a high degree of fear and anxiety during the period of VAD support. Fear is focused around the roles and responsibilities of caring for the VAD recipient, and many express concerns regarding their ability to fulfil this role effectively (Casida, 2005). Taking on the role of caregiver can be overwhelming and burdensome (Kaan et al. 2010; Marcuccilli and Casida, 2011), and there have been indications that there is need for social support for caregivers (Egerod and Overgaard, 2012).

Furthermore, caregiving for the VAD recipient involves taking responsibility for the patient in times of emergency. VAD dysfunction may reduce blood flow to the brain leaving the patient incapable of recognising and dealing with the problem themselves, as such the responsibility

falls to the caregiver meaning the life of the patient may be in their hands (Kirkpatrick et al. 2015). Caregivers also report fear of losing their loved one, this fear has two components, fear that the patient will die and fear that they will not be the same person after the experience (Kaan et al. 2010). Finally, fear can arise from the appearance of the VAD; caregivers report attempts to protect the patient from the horror of the appearance of paracorporeal style VADs (Chapman et al. 2007).

Studies of caregiver experiences indicate that adoption of the caregiving role precipitates a disruption to normal social roles. Additionally, caregiving demands are often in addition to existing roles, the balancing of which is potentially stressful (Casida, 2005). However, female caregivers have expressed that they feel that they have little choice about adopting the caregiving role, as wives it is expected of them by society, although they would not trust anyone else with the responsibility (ibid.). Indeed, it has been suggested that many caregivers accept and identify with the role of caregiver to such a degree that they neglect their own needs (Baker et al., 2010).

Caregiving has been likened to taking on a parenting role, as such it may be more difficult for spouses to adopt than parents (Kaan et al. 2010). Conflict may be experienced when attempting to adopt the dual roles of spouse and caregiver. Further, receipt of the VAD can precipitate changes to spousal relationships, including improvements to sexual relations, and connectedness (Marcuccilli et al. 2011). However, patients have also indicated that their initiation of sexual relations are often met with spousal reluctance, they suggest that this reluctance is related to concerns about the potential dangers of engage in sexual behaviours that may endanger the external components of the VAD.

2.7 Gaps in the VAD literature

The discussion above provides an overview of the current literature that explores the experiences of VAD patients and their caregivers. This research uncovers some important facets of this experience. However, there are still gaps in our understanding of this phenomenon. In this final section of the literature review, I outline some of the key gaps in our understanding and the contribution that I hope this project will make to our knowledge of this phenomenon.

Much of the recent literature exploring the experience of VAD patients has focused on VADs as a DT rather than BTT. Whilst there will be some features that are common to both of these utilisations of the VAD, there will also be important differences. One key difference is the intention of VAD support, for those with the VAD as a DT the device is intended to be a

permeant feature, whereas in BTT the device is only intended as a temporary solution. Indeed, studies that have included both BTT and DT patients have indicated that those BTT adapt less well to the device (Modica et al. 2015). Furthermore, a metasynthesis of caregivers found the experience differed depending on whether the patient is BTT or DT (Magid et al. 2015). Research originating from the US appears to be increasingly focused on VADs as a DT. Whilst this reflects the changing use of VADs in US, with DT now accounting for a significant proportion of those fitted with VADs. The experience of those BTT should not be neglected as this still accounts for a significant proportion of patients, especially in the UK.

Another limitation of existing literature is the small sample sizes utilised in many of the studies. Until recently, the majority of qualitative studies have been very exploratory, employing samples of less than 10 patients (Baker et al. 2010; Casida 2005; Casida et al. 2011; Marcuccilli et al. 2011; Zambroski et al. 2009). Several of these studies also fail to provide detailed information on the sampling procedure (Casida et al. 2005; Casida et al. 2011; Marcuccilli et al. 2011); as such, it is unclear whether these have been theoretically sampled. The size of the samples in these studies and the lack of detail regarding the sampling procedures may raise questions about the findings. More recent studies, focused on decision-making processes, have recruited larger numbers of participants, up to 45 in one case (Blumenthal-Barby et al. 2015; Bruce et al. 2015; McIlvennan et al. 2014). The present study seeks to provide add to the understanding of the experiences of VAD recipients by presenting an in-depth exploration of the phenomenon through theoretical sampling.

A final limitation with the studies presented above is that much of the literature originates from the US and Canada. Further, the majority of the recent literature is from two research groups. Differences in healthcare systems, VAD commissioning and rates of transplantation will influence the transferability of the findings between countries. The literature exploring the experience of VAD support originating from the UK is extremely limited. This study seeks to explore the experience of a UK sample where the VAD program may still be considered to be in its infancy.

2.8 Conclusion

This chapter has considered some of the literature of relevance to the topic of this thesis, the experience of 'Being' a VAD recipient. This has included a brief overview of medical sociological theories of chronic illness. I have also presented literature that explores the impact of medical technologies and the breaking down of boundaries between organic and

mechanical entities. This literature is important for understanding some of the issues that are discussed later in the thesis.

This chapter also outlined the existing literature exploring the experiencing of living with a VAD. I outlined some of the key findings of this literature, including the experience of the VAD as a source of fear and anxiety and a disruption to identity. I have also outlined the limitations with this existing literature that indicate the need for further study in this area. These are as follows. Firstly, there is a lack of literature originating from the UK the majority of research originates from the US and Canada. Secondly, existing research has for the most part utilised small, relatively, unselective, samples. Thirdly, there has been an over emphasis in recent literature of the experience of VADs as a DT over BTT. As VADs are not currently offered as a DT in the UK this limits the extent to which existing findings can be extrapolated to a UK population.

In the chapter that follows, I introduce interpretive phenomenology as the theoretical background to the study. I discuss the origins of this philosophical perspective and its appropriateness to this research project.

3

Theoretical approach and research issues

Chapter 3. Theoretical approach and research issues

3.1 Introduction

This chapter, and the one that follows, address different aspects of the design of my study. Although these chapters are inextricably linked, I have separated them in order to allow for focus to be given to separate issues. This first chapter focuses on the philosophical underpinnings of the theoretical approach used in the study, whereas chapter 4 focuses on the practicalities of data collection and analysis. An entire chapter has been given to outlining the methodological basis of the study, in order to avoid the potential weaknesses of other researchers who have espoused phenomenological techniques without justifying why they have adopted such an approach (Maggs-Rapport, 2001).

This chapter considers the methodology employed in this research project, and the choices underpinning the research design. Silverman (2000:99) defines methodology as ‘how one will go about studying any phenomenon’. This chapter provides an outline of the theoretical approach of the study. I provide an outline of this methodology and its appropriateness for this research project. Throughout this chapter, I argue the case for using interpretive phenomenology for this research area, as I believe it to be the approach most in keeping with the aims of this study. It offers the researcher the potential to uncover, what is referred to in phenomenological terms as the ‘lived experience’ of those living with VADs.

3.3 Descriptive phenomenology

I turn now to the theoretical underpinnings of this research project. Carr (2006) suggests that methodology must be grounded in a form of a priori theoretical knowledge, such as a ‘philosophy’. The philosophy chosen for this study is phenomenology. To provide the reader with an understanding of this approach and its appropriateness for this research project, I begin with a discussion of the origins of phenomenology, before outlining some of the various phenomenological approaches and the differences between them, finishing with a rationale for the approach assumed in this study. The philosophies of Husserl and Heidegger are discussed in detail, with attention also given to Merleau-Ponty. Whilst the philosophical tradition clearly goes beyond these three philosophers, they are key figureheads within this tradition, which makes them a natural starting point for discussion (Outhwaite, 1987).

Etymologically the origins of phenomenology are from the Greek words *phaniomenon* and *logia*. *Phaniomenon* meaning ‘that which appears or is seen’ and *logia* ‘to speak’. Combined these terms mean ‘the setting forth or articulation of what shows itself’. Phenomenology

views intentionality as the defining and even exclusive feature of experience. It ‘glories in the concreteness of person-world relations and accords lived experience, with all its indeterminacy and ambiguity, primacy over the known’ (Wertz, 2005:175).

Modern phenomenology was developed by Edmund Husserl in 1900-1901 in order to reinvigorate philosophy by referring it to the life of the living human subject. Husserl (1970) was critical of the natural sciences, which he believed to be taking the world for granted. Husserl perceived a disparity between the concerns of the natural sciences and the objects with which consciousness consists. He believed that the natural sciences were not appropriate for the study of conscious experience as they failed to provide a complete and exhaustive account of reality. Husserl believed that there was an essential nature to phenomena that could be described, this was the focus of his phenomenology (Todres, 2005).

Whilst the natural sciences endeavour to go beyond what is given to consciousness, the concern of phenomenology is precisely what is given to consciousness. Consciousness should not be viewed naturalistically as part of the world, as it is the reason there is a world for us in the first place. As such, the natural sciences do not offer appropriate means for the study of consciousness. When Husserl developed his phenomenology he was attempting to bring philosophy back from abstract metaphysical speculation in order to come into contact with the matters themselves, with concrete living experience (Moran, 2000).

Phenomenology endeavours not only to say that something “is” but also to identify what it is that motivates a conscious creature to say that something is. The emphasis of phenomenology is on getting to, what they describe as, ‘the truth of matters’, to describe phenomena in the broadest sense. Phenomenology concentrates on the character and structure of the experience rather than the underlying factors that may be responsible for it, aiming to describe phenomena as they appear to consciousness. Intentionality formed a major component of Husserl’s (1970) phenomenology. Husserl believed that all conscious experience, in so far as it exhibits intentionality, has an essential structure that is independent of the individual whose experience it is (Cerbone, 2006).

The nature of phenomenology has been demonstrated with the following example (Cerbone, 2006). Whilst reading the words on this page you are engaged in a visual experience, the act of seeing. If asked to describe what you are seeing you may refer to the words, letters or shape of the page. These pages or words are the object of your perception. Now consider that you are asked to describe your experience of seeing these objects, shifting your attention away from the thing that you are seeing to the actual visual experience of seeing them itself. Any visual experience is of something, it has an object, and this is what is meant by intentionality.

Our experience of something involves more than what is seen momentarily. Although it is not possible to see the entirety of the page at the same time, our experience intimates that there is more to be seen. These moments of experience hang together by pointing towards other possibilities of experience; they are bound together by being about a specific thing.

Further, in Husserlian phenomenology any given moment of experience involves more than what is experienced as being currently present. Experience involves the retention of past experiences and an expectation of future ones. There is a horizontal structure to our experiences, this is illustrated with the following example. Upon listening to Beethoven's 5th symphony, or any other piece of music, we do not experience the note currently being played in isolation, but we both retain previous notes and expect future ones. This combination of moments of experience and their horizons produces the melody that we experience (Cerbone, 2006). In terms of the phenomenon of interest in this study, the experience of receiving and living with a VAD is not experienced in isolation, but in the context of previous experiences of illness, healthcare and medical devices.

3.3.1 Phenomenological reduction

The aim of Husserl's phenomenology is to produce a rigorous and unbiased study of things as they appear; in order to achieve this the phenomenologist is required to engage in several processes of reduction.

Husserl intended to study the 'lifeworld'; what is experienced pre-reflectively without resorting to interpretations. He believed that it was possible to produce a pure description of something before it is reflected upon by focusing on the primeval form of what is immediate to our consciousness. A suspension of the natural attitude is required to achieve this. This involves putting aside all scientific, philosophical, cultural and everyday assumptions about the phenomenon of interest. Further, we must suspend all questions pertaining to the causal factors; this paves the way for asking transcendental questions about the possibility of experience. This process of freeing oneself of presuppositions is known as the 'epoché', it directs the researcher's attention towards the conscious phenomena, facilitating the discernment and the description of essential structures.

Furthermore, the search for essences also involves the engagement in a second stage of reduction: eidetic reduction. Eidetic reduction involves the removal of arbitrary or contingent features of the experience to isolate the necessary structure of the phenomena. To identify the arbitrary features the phenomenologist varies the experience through imaginative variation, where features of the experience are removed whilst asking the question 'What can I change

or remove without losing the phenomenon?’ There will be limits to the variations possible and transitions where the experience breaks down entirely. Those features whose removal causes the experience to break down are essential components of the phenomenon. For example, an essential feature of the experience of VAD recipients is the merging of self and ‘not-self’ that occurs following the device implantation. Removal of this feature would lose the meaning of what it means to ‘Be’ a VAD recipient. This process of imaginative variation allows the phenomenologist to identify the features of the experience that are essential to the phenomenon.

3.4 Interpretive phenomenology

A second major phenomenological tradition is Martin Heidegger’s interpretive phenomenology. Heidegger (1962) defines phenomenology as ‘to let that which shows itself be seen from itself on the very way in which it shows itself from itself’ (ibid.: 58). Heidegger’s phenomenology intends to bring forward and make manifest what is normally hidden in human experience. Despite Heidegger beginning his phenomenological career under Husserl at the University of Freiburg, there are notable differences in their approaches. In particular, Heidegger rejected the possibility of achieving a description of the pure “essence” of a phenomenon. Instead, he suggested that all we can hope to study phenomenologically is an individual’s interpretation of their experience of a phenomenon.

The ancient Greek myth of Orpheus and Eurydice has been used to explicate the futility of trying to produce a pure description of a phenomenon (Van Manen, 2006). Eurydice, Orpheus’ wife, dies and he implores the Gods of the underworld to return her to him. The Gods, moved by his pleas, allow him to have his wife back on the proviso that he does not look at her until they reach the upper world. However, Orpheus turns to look at his wife before they reach the upper world and she is borne away. The common interpretation of this myth is that Orpheus forgets the condition of his wife’s return and desires to see her. However, Blanchot (1981) suggests that it is not desire that motivates Orpheus, rather he is trying to see the meaning of love itself; he is trying to see what is invisible. This has been likened to the endeavour of writing phenomenologically; there is always a tension between presentation and representation (Van Manen, 2006). In the endeavour of trying to produce a pure description, the language we use substitutes itself for the phenomenon. Returning to the metaphor of Orpheus, Orpheus is the phenomenological writer and his wife is the secret meaning that the phenomenologist is pursuing. The gaze of Orpheus, or the phenomenologist,

unwittingly destroys what it is seeking. The pure description of a phenomenon, as advocated by Husserl, may not be attainable however, it is possible to produce an interpretation.

Heidegger also rejected Husserl's stance on bracketing. For Heidegger the concept of bracketing out all theory and prior knowledge was both unacceptable and unachievable. He argued that our consciousness is essentially engaged in the world, and it is not possible for a person to extract themselves from the world in which they live as their experience is 'already within the world' (Rapport, 2005: 129). Moreover, Heidegger suggested that presuppositions might actually provide a valuable guide to phenomenological inquiry, making it a meaningful undertaking. Our experiences are essential for us to understand a phenomenon, to make sense of something we must have some experience to use as a frame of reference. For example, how can we understand what someone means when they say they are hungry, if we have no experience of hunger ourselves? (Colaizzi, 1987). Our experience of a phenomenon is always influenced by our previous experiences and historicity (Van Manen, 2006). Bracketing all preconceptions and previous experiences may be a futile endeavour, indeed it may be more fruitful to try and understand the effects of these experiences rather attempt to eliminate them entirely (Porter, 1993).

Heidegger's interpretive phenomenology fused Dilthey's hermeneutics with Husserl's descriptive phenomenology, to produce a hybrid discipline. The concept of hermeneutics originates from the Greek god Hermes, who was responsible for interpreting messages between the gods (Thompson, 1990). 'Hermes was a go-between gods and humans, who tells lies as well as truths, who misleads as well as leads. Hermes represents the untrustworthy yet necessary link between worlds' (Dermot, 2006:217). Hermeneutics are essential to the understanding of another's experience, which we must interpret in order to make sense. However, the myth of Hermes highlights the contradictory nature of interpretation, which can both reveal and conceal things.

Heidegger's major work, *Being and Time*, focuses entirely on the question of Being, which he believed had been neglected by philosophy (Mulhall, 1996). Whilst thought provoking, Heidegger's *Being and Time* also has the potential to be obfuscating (Moran, 2000). Confusion may be particularly acute for readers of the English translation where the word 'being' is used in reference to two separate concepts (Large, 2008). Understanding is aided by the clarification between two fundamental terms, 'being' and 'Being'. In German, the original language of the text, there are two different words for these distinct concepts. For clarity 'being', with a lowercase 'b' is used in reference to any entity that exists in our world, all humans, animals and inanimate objects are 'beings', whereas 'Being' with a capital 'B' refers

to an analytical interpretation that reveals the most primordial condition of beings in their contextual framework.

Heidegger uses the term *Dasein* to refer to the human way of Being in the world, which is unique from all other beings in the world. It has been suggested that Heidegger employs this term to break us out of our preconceived ideas and stress the situatedness of human reality (Walters, 1995; Large, 2008). Whilst usually left untranslated in English texts, *Dasein* is literally translated as 'being there'. *Dasein* is more significant than any other being, because it is the only being for whom the question of Being can be a question at all (Heidegger, 1962). Human experience has an ontological character that is entirely lacking for any other being. We are the only beings who can worry about who we are, what we are doing and whether we are doing it right. Whilst an animal might worry about where its next meal is coming from, it does not worry about what it means to be an animal. This 'making sense of life' is a uniquely human problem (Large, 2008). Meaning, as conceptualised by Heidegger, is that which allows us to understand the focus of our attention as the thing it is. A concept that is demonstrated using the following example: upon entering a new town you ask what a building is, you are told it is a theatre. In order for this explanation to be useful to you, a prior understanding of theatres is required. If, however, you are unfamiliar with the concept of a theatre then further steps will be required for understanding (King, 2001).

Heidegger suggested that understanding of Being can be achieved through accounts of *Dasein* in their average everydayness. *Dasein*, 'being there', is always captured and enslaved by its past; we live the past through the present and the present through the past. Awareness of the historicity of understanding that governs our prejudices is an essential aspect of interpretive phenomenology. To ignore this historical understanding would distort our knowledge and the interpretations drawn from data. Heidegger used the term 'fore-structures' to refer to this historical understanding, it is what is known or understood in advance of interpretation. This goes beyond the idea of background knowledge, rather it shows that interpretation already exists in a fully formed state, it does not require expression (Mackey, 2005). Heidegger believed that interpretation was a circular process that involved moving back-and-forth between parts and the whole and fore-structures of understanding and what is learnt from the investigation (Kumar, 2012).

In interpretive phenomenology, the researcher develops meaning by questioning prior knowledge and expanding the horizons of meaning. This process is illustrated by the hermeneutic circle. Heidegger believed that interpretation was a circular process where fore-structures of understanding become explicit and are considered in terms of the whole

understanding of something (Mackey, 2005). The hermeneutic circle demonstrates this circular process of understanding, which involves the back and forth movement between partial understandings and a more complete whole. The answer to the question is disclosed to us in light of what we already know. Whilst this process is circular, it is neither closed, nor vicious but rather there is a certain relatedness backwards or forwards. It is never possible to reach a full understanding of the meaning of a phenomenon as we are constantly presented with new meanings to explore. To manage this, interpretive phenomenology demands self-reflexivity of the researcher. This includes engaging in on-going conversations about the experience whilst simultaneously living in the moment, actively constructing interpretations about the experience and questioning how these came about.

Another key component of Heidegger's phenomenology is his assertion that human experience, identity and time are all inextricably interwoven. Our experience of time is at the centre of how we experience our identity and existence. We are temporally situated-in-the-world; our past, future and present are experienced as a unity. Furthermore, Heidegger differentiates between authentic and inauthentic time. Authentic existence is always directed towards the future as something open, never fixed or complete, whilst inauthentic experience is governed by the provisional needs of ordinary time. Further, it has been suggested that viewing time and identity as inseparable entities that are bound up with the future direction, may aid in the development of effective interventions (Gergel, 2013).

Much of the phenomenological basis of this study is informed by concepts from Heidegger's *Being and Time*. However, this work fails to fully account for the role of the body in orientating our worldly acts and practices (Aho, 2005). As the focus of this study is on the lived experience of VAD recipients, a device that is implanted into the body, it is essential to account for the role of the body in our experience. Whilst Heidegger addressed this gap in his later Zollikon Seminars (2001), his approach is said to bear a striking resemblance to that of French philosopher Merleau-Ponty (Aho, 2005). As such, it is to Merleau-Ponty whom I now turn for a greater understanding of the role of the body in our perception of the world.

3.5 Phenomenology and the body

Merleau-Ponty, a French phenomenologist, focused his major work 'The phenomenology of Perception' (1962) on revealing the structure of perception. Embodiment is a characteristic in Merleau-Ponty's account; we experience the world through our bodies. Merleau-Ponty highlights the significant differences between the experience of one's own body and experience of everything else. He rejects the idea of the body as a mere object in the world,

rather presenting it as a form of consciousness (Romdenh-Romluc, 2011). Phenomenologists suggest that the most common manner of experiencing the body is in a mode of near self-forgetfulness (Van Manen, 1998). Under normal circumstances, the body is the subject of one's perceptions rather than the object. The structure of our bodies confers certain motor skills upon us, such as walking, which are acquired through the repeated engagement in bodily activity until such time as we become proficient, allowing us to perform these without the need for conscious attention. Merleau-Ponty refers to this as motor intentionality. This is our basic embodied contact with the world. One's bodily self knows how to act and has a motor understanding of its surroundings, the body is a form of consciousness, human subjects are 'beings-in-the-world'. Merleau-Ponty suggests that the body schema is integral to a unifying theory of perception; all forms of experience are mediated by close interaction between the body and the environment. (Klinke, Thorsteinsson and Jónsdóttir, 2014).

However, Merleau-Ponty (1962) suggests that following the development of a disease or illness the world becomes incomplete. Our well-being may become disturbed, and in this self-forgetfulness, we come to discover our own body. These changes to embodiment can affect the spatial structure of an individual's experience. The experience of illness can put an individual at odds with their body, and the body's failure to function 'normally' can bring it into sudden awareness (Morris, 2008; Toombs, 1990).

3.6 Phenomenology as a research methodology

As phenomenology is in essence a philosophical tradition, much of the discussion above has focused upon it as a philosophy rather than as a research methodology. However, following an explosion in the 1970s, phenomenology is increasingly employed as a methodology for qualitative inquiry, particularly in health research. This section of the chapter focuses on the use of phenomenology as a research methodology, and what adaptations are needed for the application of it in this manner.

Researchers have aimed to demonstrate that it is possible to elucidate a methodology from Heidegger's philosophy to underpin the methods of phenomenological research (Johnson, 2000). However, there is no step-by-step method for undertaking interpretive phenomenological research, which seeks to avoid method for method's sake (Kafle, 2011). As such, difficulties in applying phenomenology as a methodological basis for a study may arise from these lack of guidelines for the practical undertaking of the approach. This lack of guidelines have been noted as a source of frustration for researchers wishing to adopt this

approach (Groenewald, 2004). This is compounded by a lack of consensus about how phenomenology should be practically applied (Finlay, 2012).

Van Manen (1984) provides some of the most in-depth guidelines on what makes a study phenomenological, outlining four essential characteristics. Firstly, turning to a phenomenon that seriously interests us and commits us to the world; investigating experience as we live it rather than as we conceptualise it; reflecting on the essential themes that characterise the phenomenon; and finally describing the phenomenon through the art of writing. He defines phenomenological research as the search for the 'fullness of living' (Van Manen, 1984: 2).

Giorgi (1989) has also suggested four key characteristics that should hold across all phenomenological variations: the research is rigorously descriptive; explores the intentional relationship between persons and situations; uses the phenomenological reductions; and discloses the essences, or structures, of meaning immanent in human experiences through the use of imaginative variation.

Additional issues arise from the fact that some aspects of phenomenology, particularly Husserl's descriptive approach, appear at odds with the realities of contemporary qualitative research. In order to understand an aspect of human experience, phenomenological researchers borrow the descriptions of others (Van Manen, 1984). This allows them to become more vicariously experienced in the phenomenon (Van Manen, 1984; Giorgi, 1997). However, adoption of a Husserlian descriptive phenomenological approach would require both the researcher and participant to bracket out their presuppositions. Whilst it is common for researchers to engage in bracketing, participants rarely engage in this practice as such as the descriptions they provide are not necessarily primordial.

3.6.1 Disputes about phenomenology in social science

In response to some of the issues outline above, a new approach was developed to facilitate use of phenomenology in research, interpretive phenomenological analysis (IPA) (Smith, Harré and Van Langenhove, 1995). IPA is an approach to data analysis that involves a detailed analysis on a case-by-case basis, the focus is to try and get close to the personal world of the participant (Smith and Osborn, 2003). IPA can be seen as an attempt to operationalise phenomenology, moving it away from its philosophical roots to a more user-friendly approach (Pringle, 2011). Supporters of IPA have suggested that it brings forth the study of meanings, experiences and subjectivity (Todorova, 2011), striking an important balance between philosophical and theoretical foundations whilst presenting them in an accessible way. However, there is a dispute as to the extent to which IPA can be considered

truly phenomenological. Finlay (2009) criticises its failure to employ Husserlian techniques. Further, there are questions as to whether it differs significantly from interpretive phenomenology, 'IPA is strongly connected to the interpretive or hermeneutic tradition' (Plamer, 1969:40). Further, IPA's assertion that a single case may be sufficient for analysis raises questions about the transferability of findings (Pringle, 2011).

IPA is not, however, the only dispute emerging from contemporary uses of phenomenology. Bracketing is often misused by researchers who equate this practice with phenomenology regardless of the philosophical framework being used (LeVasseur, 2003). Furthermore, descriptions of bracketing in research reports are often ambiguous and imprecise. It has been suggested that this arises from a disconnection between bracketing and its basis in phenomenology (Gearing, 2004). These problems in the application of phenomenology may stem from a lack of understanding about the traditions of phenomenology amongst some researchers employing the approach. Indeed, in an analysis of the use of Husserl's phenomenology in nursing research, Paley (1997) found that researchers described 'identifying and putting aside' preconceptions when reference to bracketing. They suggest that whilst this may be a valuable research technique in itself, it is also a misunderstanding of Husserl's terminology. Further, Paley (1997) also claims that research reports often offer no explanation of what an essential structure is or how it has been generated, and it is often unclear what justifies the move from that which is subjectively meaningful to that which is essential to the phenomenon.

Furthermore, Draucker (1999) conducted a study investigating the Heideggerian hermeneutics in nursing research. They found much variation in how specific Heideggerian concepts were used to inform interpretation. They suggest that the dynamic fluid process of hermeneutics should be evident in the description of research activities. Moreover, they suggest that these reports using Heidegger's phenomenology should include a reflection of how the philosophy has enriched interpretation.

Disputes about the use of phenomenology may arise from a tendency for researchers to rely on second-hand sources to inform their methodological position. In nursing research in particular there appears to be a tendency for researchers to cite other nurse researchers who have espoused phenomenology rather than turning to the original texts (Paley, 1997). This reliance of second hand sources may result in a misunderstanding of some of the meanings of phenomenology's key terms. It may be difficult for the novice researcher to be sure that the studies by which they clarify their approach are judiciously informed by the philosophy that is

held to guide them (Caelli (2001). A problem that is intensified by the lack of concrete guidelines for phenomenology, as discussed above.

Whilst difficulties in applying phenomenology as a research are evident, the use of phenomenology can often be seen as more of challenge than it needs to be (Caelli, 2001). Although not always applied appropriately, phenomenology can be an appropriate and useful methodology to inform research. I now outline the manner in which phenomenology has specifically informed this study.

3.7 The phenomenological approach of the current study

Phenomenology has been suggested as an appropriate methodology for the investigation of phenomena that are central to the lived experience of human beings but not well understood (Carpenter, 1995). Phenomenology is an appropriate choice for this study because it focuses on human experience as a topic in its own right (Langdridge, 2007). Heideggerian phenomenology, specifically with references to its stance on temporality, has provided a useful approach to previous investigations into the experience of chronic illness (see for example Gergel, 2013; Morris, 2008; Papadimitiou and Stone, 2011; Toombs, 1990). Previous researchers have justified their use of Heidegger's phenomenology as an approach for investigating experiences of illness because it affords space in which the participants can give voice to their experiences in a manner which is open and non-structured (Robertson-Malt, 1999), which is the intention of this research project.

I chose a Heideggerian phenomenological approach for this study above a Husserlian as I felt that 'pure description' of the experience of 'Being' a VAD recipient is an unobtainable goal. Whilst this study aims to provide an account of experiences of living with a VAD, it is acknowledged that the final account will be an interpretation. I do not believe that it is possible for the researcher to completely put aside their presuppositions and experiences of a phenomenon. Thus, instead of attempting to bracket these out completely a reflective journal was kept. The reflective journal allowed me to record and reflect on my evolving presuppositions regarding the phenomenon before, during and after data collection.

The following chapter will outline the specific methods employed in this study; this includes a reference to the underpinning interpretive phenomenological methodology and the manner in which this influenced the methods chosen.

4

Methods

Chapter 4: Methods

4.1 Introduction

The previous chapter outlined the methodological basis for the study. In this chapter, I turn to the specific research process adopted. The intention of this chapter is to document the fieldwork process as it evolved throughout the study. Firstly, I begin with an introduction to the recruitment process used in this study and a justification of the sampling methods used. Following this, I introduce the respondents; firstly by providing characteristics of the group as the whole, then by giving a brief biography for each participant in turn. Attention is then turned towards my role as the researcher; acknowledging the ways in which I may have influenced the data collected, I outline how these issues were dealt with to minimise impact. Finally, I outline the data analysis process, detailing the process by which the major themes were uncovered.

4.2 Recruitment

The initial plan for the study was for a comparison of the experience of waiting for a heart transplant, with or without a VAD. This was to include two participant groups, those on VAD support whilst waiting for a heart transplant, and those who were not. However, the focus of the study changed once data collection began with the VAD supported group. Data collected from these participants, coupled with a growing awareness of paucity of research investigating experience of these individuals, led to the decision to give sole focus of the study to the experience of 'Being' a VAD recipient.

When designing the study, consideration was given as to who should be included in the study sample. One of the key decisions related to the inclusion of paediatric VAD recipients. Whilst it was acknowledged that data from paediatric VAD recipients and their caregivers would be extremely interesting, it was decided against including them in the final protocol of the study for several reasons. Firstly, it was thought that the limited number of paediatric VAD recipients would make it difficult to achieve a sufficient sample within the time constraints of the study. Secondly, at the time of developing the study protocol there was discussion amongst NHS commissioning bodies about moving the provision of heart services for children away from the transplant centre from which we were recruiting. This created a degree of uncertainty as to whether it would be possible to recruit sufficient paediatric participants within the time constraints of the study. Ultimately, it was decided that the experience of paediatric VAD recipients would probably be markedly different from those of adult participants. As such, I decided that paediatric VAD recipients would warrant a study in their own right, so it would not be appropriate to include them in this study.

In order to begin data collection it was necessary to gain access to the VAD recipients; this involved negotiating with 'gatekeepers'. Gatekeepers have been defined as those with the power to grant or withhold access (Burgess, 1984). There were two forms of gatekeepers in this study. Firstly, it was necessary to gain access through the organisational gatekeepers; this involved securing approval from the National Research Ethics Service and the NHS Trust Research and Development office (Reference: 12/NE/0218, for the approval letter please see Appendix 2). The second form of gatekeepers were the clinical team at the specialist hospital, specifically the consultant cardiologist and specialist VAD nurses. Before undertaking the research, I arranged to meet the key staff members in order to establish a relationship.

Recruitment to the study involved the gatekeepers identifying and approaching potential participants. Clinical staff approached potential participants with details of the study. Those who reported their interest in participating were contacted by myself and sent the study information; this consisted of an invitation letter, a participant information sheet, and an expression of interest form. Potential participants were asked to return the form if interested in participating in the study. Upon receipt of the expression of interest form, I contacted potential participants to organise a suitable time to conduct the interview. Participants had the option to withdraw for the study at several time points in the recruitment process. Figure 9 demonstrates the recruitment process for the interviews.

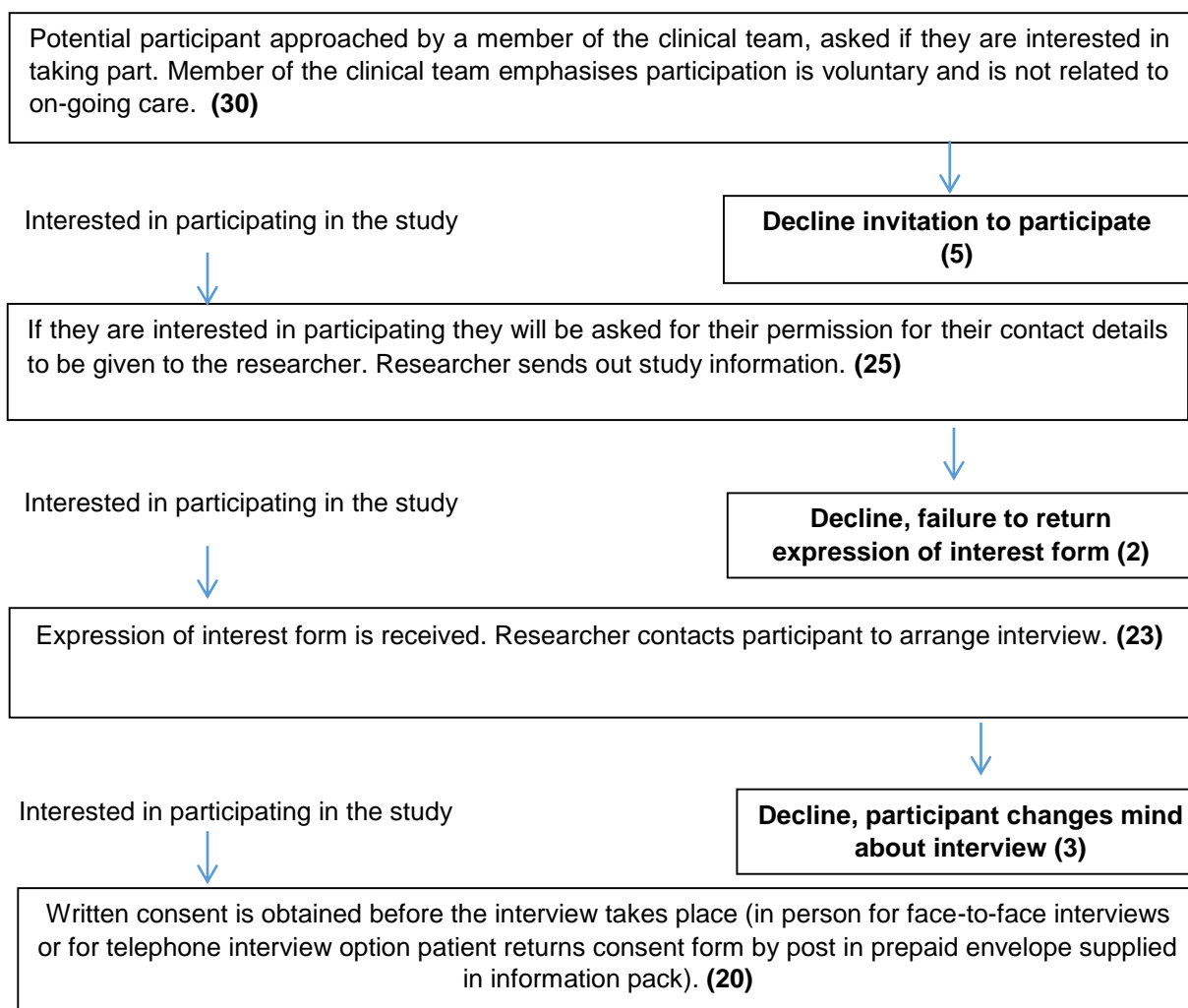


Figure 9: Recruitment Process for Interviews

The participant information sheet (see Appendix 3) advised that VAD recipients could nominate a family member or carer to sit in on the interview or take part on their behalf. This allowed participants who may not have felt well enough to participate on their own to have a significant other provide a proxy account of their experience. I considered the potential impact of interviewing in dyads. Benefits from interviewing couples together have been observed previously (Bjørnholt et al. 2014). Furthermore, it has been suggested that joint interviews account for the fact that illness is lived and understood within the individual's social context (Sakellariou et al. 2013), and interpretive phenomenology highlights the importance of placing interpretations about individual's experiences within the context of their lives (Finlay, 2012).

However, joint interviews had the potential to limit participants' responses. It was acknowledged that the presence of a significant other might lead participants to censor

responses to certain questions, particularly those pertaining to mortality and death. Ultimately, it was felt that it was better to accept this potential limitation rather than limiting the potential participant pool. Further, it was felt that offering participants the choice of including others in the interview would offer them some control over the situation, ensuring they felt as comfortable as possible in the research setting.

4.2.1 Sampling

As the aim of this study is to explore the experience of 'Being' a VAD recipient, I aimed to sample as wide a range of the experience of living with a VAD as possible. In order to achieve this, purposeful sampling was used to explore certain issues with each round of sampling. Purposeful sampling is when an individual is selected based on a specific characteristic that they hold (Patton, 1990).

For the initial round of sampling, I asked the gatekeepers to identify individuals that they viewed to be 'typical' VAD recipients. This led to the recruitment of three participants. Following these interviews an initial analysis of the transcripts was performed. This led me to seek some specific cases for the next round of interviews, specifically those who had experienced problems in living with the VAD, and were unhappy living with the device, this resulted in the inclusion of two more participants. In the third round of sampling, I sought to explore a number of issues: living alone with the device, living with the device long term, over two years, and remaining an inpatient. This led to a further four interviews. The focus of the fourth round of sampling was to explore VAD recipients' hopes and expectations for the future; I sought opposite ends of the spectrum, those who did and did not want a heart transplant, and this resulted in two interviews. Up to this point, all participants were male, as such in the fifth round of sampling I specifically sought out a female VAD recipient and a recipient who had returned to work with the VAD. The final round of sampling sought to explore the issue of community and adherence to medical regimens and VAD management. A visual representation is provided below in figure 10.

During data collection, a break of around six months was taken where I did not sample any additional participants. This decision was taken after 14 interviews had been conducted. The purpose of this break was to allow me to give complete focus to the data already collected, and the themes that were beginning to emerge. Further, this allowed me to identify specific issues that required further elucidation in later rounds of sampling.

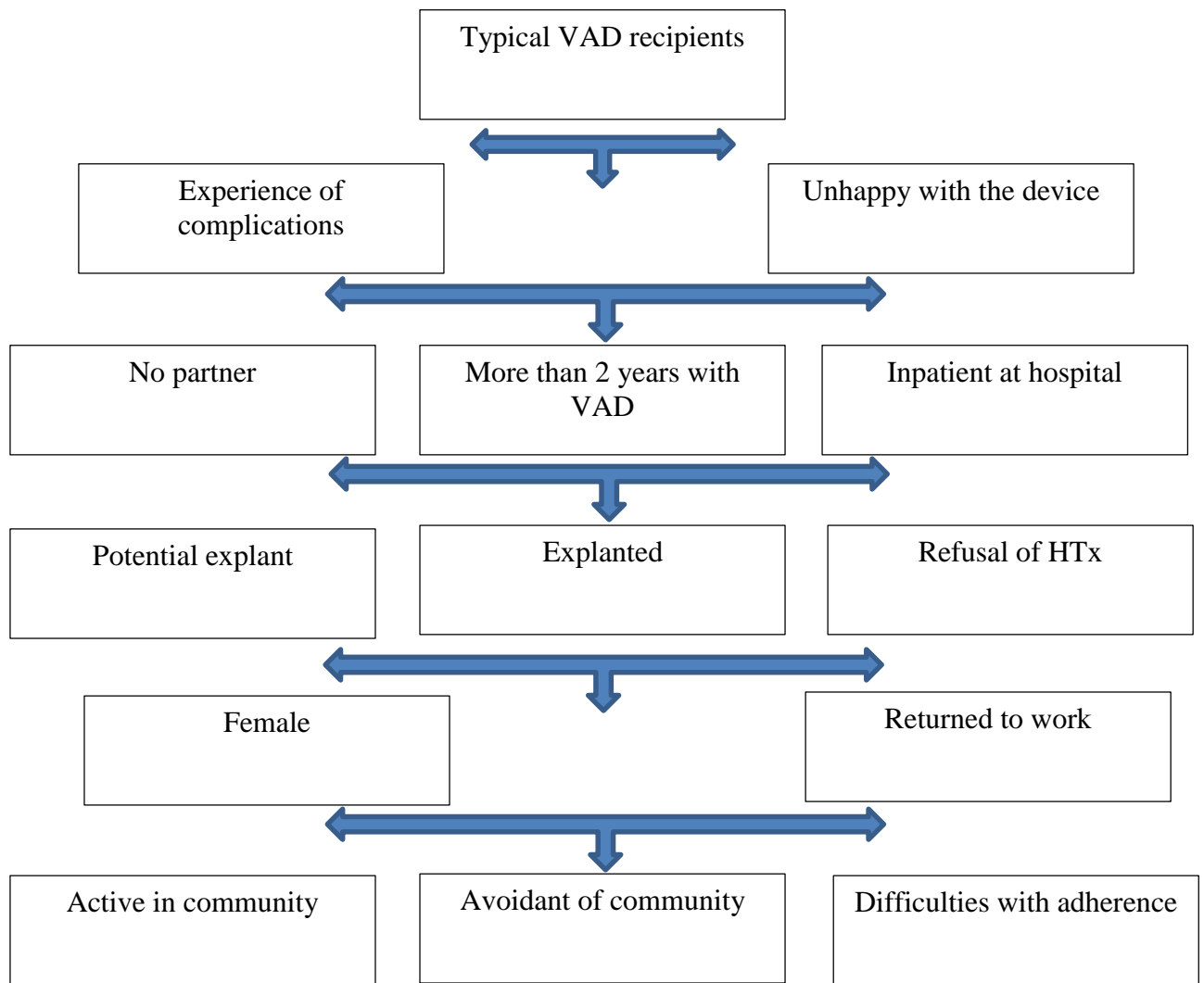


Figure 10: Sampling procedure

As with any study there were hard to reach individuals within the VAD recipient sample. In particular, it was difficult to recruit those who were identified by clinicians as having low engagement levels amongst the VAD community. Attempts were made to recruit some of these individuals; however, it did not always prove possible. One individual identified as a potential participant said they were not interested in participation in the study at the point of first contact. Whereas, others appeared initially interested in participation but dropped out at a later date, choosing not to return expression of interest forms or failing to respond to attempts to set an interview date, these individuals were considered to have withdrawn from the study.

As clinicians acted as gatekeepers to the VAD recipients, they have also influenced the study sample. Although I expressed interest in sampling individuals with specific characteristics clinicians had ultimate control over whom they approached about participation in the study. As such there may be individuals/groups who could have provided interesting insight into the

experience of ‘Being’ a VAD recipient but were not deemed appropriate for participation by clinicians.

4.2.2 Participants

I now turn to the research participants themselves, I begin with an overview of the interviewees as a group and will then introduce them individually.

In total I conducted 20 interviews. This included 9 one-to-one interviews, and 11 two-to-one interviews where a partner or family member was also present. Seventeen of those interviewed were male, and three were female³. Interviewees’ ages ranged from 21 to 68 years. There was also great variation in the respondents’ experiences of heart failure that had resulted in the receipt of the VAD; whilst eight had no experience of heart failure prior to the acute event that prompted the need for the VAD, others had been living with the condition for a number of years or even decades. 17 of the interviewees had partner, 15 of whom were cohabiting, 3 were single. Partners were present in 11 of the interviews. 14 of the interviewees had children, 3 of which were school age, 4 had grandchildren. Key characteristics of each participant are provided in Table 1, these were correct at the time of interview.

³ This is representative the proportion of male and female patients with heart failure, and living with VADs (British Heart Foundation, 2015e; NHS Blood and Transplant, 2015b).

Table 2: Demographic characteristics of interviewees

Pseudonym	Sex	Age group	Marital status	Heart failure	Time on VAD support at interview	Status at end of study
James	Male	50-54	Married	Chronic	11 months	Transplanted
Matt	Male	50-54	Married	Chronic	2 ½ years	VAD support
Paul	Male	40-44	Married	Acute	4 months	VAD support-Hoping for explantation
Darren	Male	55-59	Married	Chronic	3 years	Deceased
Fred	Male	55-59	Married	Chronic	4 years	Deceased
Simon	Male	50-54	Single- lives alone	Chronic	1 ¾ years	VAD support
Ian	Male	35-39	Married	Chronic	7 months	VAD support
Stephan	Male	45-49	Partner- lives with adult child	Chronic	11 months	Deceased
Gary	Male	55-59	Married	Chronic	2 years	VAD support
Ben	Male	21-24	Partner- lives alone	Acute	2 years	Explanted
Ned	Male	60-64	Married	Acute	2 years	VAD support
Grant	Male	25-29	Single- lives with parents	Acute	2 ½ years	Explanted
Russell	Male	55-59	Married		2 ½ years	Transplanted

Fran	Female	40-44	Separated-lives with children	Chronic	3 ½ years	Deceased following transplant
Albert	Male	65-69	Married	Acute	1 ½ years	Deceased
Jan	Female	55-59	Married	Chronic	4 years	VAD support
April	Female	50-55	Married	Chronic	3 years	VAD support
Gordon	Male	60-64	Married	Acute	1 ½ years	VAD support
Jack	Male	25-29	Engaged- lives with fiancée	Acute	3 years	Transplanted
Michael	Male	30-34	Married	Acute	6 months	VAD support

I will now introduce each of my participants individually. I believe that these biographies are important as the focus of this study is on the experience of the VAD recipients. My participants will be anonymous to the majority of people, however given the limited size of my study group I am aware that there are limitations to my ability to anonymise these individuals, it may be possible for those who are familiar with this group to identify individuals by their age, illness trajectories, and family background. It is likely that some respondents will be more anonymous than others, as some will be more easily recognisable due to factors such as their age. As part of the anonymising process, I attributed pseudonyms to each of my participants, an approach that is recommended by Orb, Eisenhauer and Wynaden (2001). My reasoning behind each pseudonym varied between participants; for some it was because they reminded me of someone I knew due to some shared characteristic, for others it was because I felt that a particular name suited the individual. Efforts were also made to anonymise references to places and events. Furthermore, I believe that a process of anonymisation occurs over time. VAD participants are a transient group, and the interviews were conducted over a period of two years, from 2012 to 2014. As such, I believe that it would be difficult, even for those familiar with the patient group, to identify specific individuals from the information given in the thesis.

James was 52 and had been living with the VAD for around 11 months, he was interviewed alone. James was on the waiting list for a heart transplant and at the time of the interview was present in the hospital for his 6 monthly eligibility check-up. James had a high level of education and had previously worked in healthcare. James had a wife, who was not present in the interview, and a young school age son. At the end of my fieldwork, James was still alive and had received a heart transplant.

Matt was 51 and had a long history of heart failure that dated back almost 20 years. At the time of the interview, Matt had been living with the device for 2 and a half years. Matt was married and living with his wife Susie who participated in the interview with him. Matt appeared to have an active role in the local VAD community, having been asked to meet with many potential VAD recipients to discuss his experiences. Matt had adult children who no longer lived with him. Matt was still alive and living with the VAD when I completed data collection.

Paul was 40 and attended the interview with his wife Hannah, with whom he lived. He had only been living with the device for around 4 months at the time of the interview following a very quick deterioration into heart failure caused by a virus. Paul was hoping to have the

VAD explanted rather than need a heart transplant. Paul was still living with the VAD and working towards explantation at the end of data collection.

Darren was 58 and attended the interview with his wife Carole. Darren was an inpatient at the time of the interview following a right heart catheter procedure. Darren had a history of heart failure dating back over 10 years. At the time of the interview, he had been living with the device for about three years. Darren was particularly memorable as an interviewee because he was dissatisfied with his life with the VAD. In particular, Darren was unhappy with his inability to return to work, which had led to concerns regarding money. Darren had grown up children who no longer lived with him. Unfortunately, Darren has died since the interview was conducted after suffering a cerebral haemorrhage.

Fred was 55; he attended the interview with his wife Nancy. Fred's heart problems could be dated back around twenty years and he was also the most established VAD patient interviewed, he had been living with the device for almost four years at the time of the interview. He was in fact one of the first patients to be implanted at the hospital, and he had a different (older) style of device to the other interviewees. At the time of the interview, Fred had recently been placed on the urgent heart transplant list after suffering from a serious driveline infection. Fred had experienced many complications whilst living with the VAD including strokes, driveline infections, and severe anaemia resulting in temporary blindness and severe gout that left him temporarily unable to walk. Fred has passed away since the interview was conducted following a cerebral haemorrhage.

Simon, 53, took part in the interview on his own. He was single and lived alone. At the time of the interview, Simon had been living with the device for a year and three quarters. Simon was on the waiting list for a heart transplant and at the time of the interview was attending the hospital for his six monthly right heart catheter procedure. Simon had been living with heart failure for over 5 years before receiving the VAD. At the end of fieldwork, Simon was still alive and living on VAD support.

Ian, 35, took part in the interview along with his wife Lyndsey. Ian had been living with the VAD for almost 7 months, and for the majority of this time had been an inpatient at the hospital. Ian had experienced many complications since having the VAD implanted which prevented him from returning home. He had been able to return home for a couple of days for a family occasion but had been readmitted a few days later following severe bleeds. Ian's condition was genetic and several members of his family had experiences of heart failure, or

had received a heart transplant, including his father who had died when Ian was a child. Ian had two young children.

Stephan, 47, had been living with the VAD for 11 months, and took part in the interview on his own. Stephan had a partner, who was not present in the interview, and lived with his adult son. Stephan had been suffering from heart failure for a number of years. Stephan had an adult son and a partner with whom he lived. At the time of the interview Stephan was an inpatient at the hospital following a couple of serious blood clots, he had been placed on the urgent heart transplant waiting list. Stephan has passed away since the interview following a cerebral haemorrhage.

Gary, 55, took part in the interview alone, although his wife was present at the hospital she opted not to participate. Gary had been living with the VAD for around two years. Gary had suffered from dilated cardiomyopathy for a number of years and had previously been fitted with a pacemaker. Gary was an active member of the VAD community and had friendships with several of the other VAD patients. At the end of fieldwork, Gary was still living on VAD support.

Ben, 21, had been living with the VAD for 2 years. Ben took part in the interview with his girlfriend Sarah. Ben lived with his parents at the time of the VAD implantation. Heart failure ran in Ben's family and his father had previously had a heart transplant. Ben's hopes for the future were focused on explantation of the VAD rather than transplantation. At the end of fieldwork, Ben's heart had recovered sufficiently to have the device explanted.

Ned, 62, had been living with the VAD for 2 years; he took part in the interview alone although he was married with two grown up children. During his time living with the VAD, Ned had experienced many driveline infections. Ned expressed the desire not to have a heart transplant unless completely necessary as he viewed the operation as carrying a large risk. Ned was still living on VAD support at the end of data collection.

Grant was 25; he took part in the interview alone. Grant was single and living with his parents. Grant had been explanted after living with the device for two and a half years, as he had experienced significant myocardial recovery for his heart to resume lone functioning. Grant acknowledged that in spite of this good outcome he would have to manage his heart condition for the remainder of his life. Grant's condition was genetic and his mother had been diagnosed since he became unwell.

Russell, 59, took part in the interview alone although he was married with grown up children. Russell had a long history of heart disease dating back around 15 years. He had been living with the VAD for two and a half years at the time of the transplant. Russell had experienced many complications whilst living with the VAD, including infections and a stroke. Russell was the only patient interviewed who had been able to return to work whilst living with the VAD. Russell was on the waiting list for a heart transplant and had received two calls to come in but neither had resulted in transplantation. Since the interview, Russell has received a heart transplant.

Fran, 41, was single and took part in the interview alone. Fran had been experiencing heart failure for ten years and had previously been fitted with an ICD and pacemaker. Fran had been living with the VAD for almost 3 and a half years at the time of the interview, and was the longest surviving female patient. Fran had three young daughters and had separated from her husband whilst living with the VAD whom she was living with at the time of the device implantation. During her time on VAD support Fran had two infections and had to have the driveline relocated. Since the interview was conducted, Fran received heart transplant but had unfortunately died following complications.

Albert, 68, was married with grown up children and grandchildren, he took part in the interview alone. Albert had been living with the VAD for just over a year and a half, his experience of heart failure had a sudden onset following a heart attack. Prior to his heart attack, Albert had been fit and healthy and invested a lot of time partaking in physical activity. Albert was an inpatient at the hospital at the time of the interview, and had been identified to the researcher as someone who was palliative by the specialist nurse. Following the interview Albert passed away after suffering recurrent gastrointestinal bleeding.

Jan aged 57, took part in the interview with her partner Terry. Jan's heart condition had a sudden onset following a heart attack 5 years ago; she had been living with the VAD for 4 years. During the time living with the VAD, Jan had been diagnosed with breast cancer. Jan and Terry had also relocated in order to live closer to the VAD centre. Both Jan and Terry were vehemently against living with the VAD in the long term. Jan was an active participant in the VAD community and was friends with several of the other patients interviewed. Jan had experienced many problems with the VAD over the period of time living with it, including electrical problems with the controllers and batteries and blood clots. At the end of fieldwork, Jan was still living on VAD support.

April aged 50, took part in the interview with her husband David. April had had a long history of heart disease, being initially diagnosed 25 years ago following the birth of her second son. April's children were now adults with children of their own. Until 5 years previously, April had experienced few complications associated with the heart disease. April had experienced difficulty deciding whether or not to have the VAD, eventually the decision had been taken out of her hands as she had dramatically deteriorated. Like Jan, April had been diagnosed with breast cancer whilst living with the VAD resulting in a temporary removal from the heart transplant waiting list. April was an active member of the VAD community and was friends with several of the other patients interviewed including Jan, Gary and Fran. At the end of fieldwork, April was still living on VAD support.

Gordon aged 61, attended the interview with his wife Gail. Gordon's heart failure had a very sudden onset and prior to which he had been fit and healthy. At the time of the interview, Gordon was in hospital for a heart transplant assessment. Gordon had adult children, one of whom had also been diagnosed with heart failure. Gordon and his wife had retired early prior to the heart attack and had a holiday home in Europe in which they spent most of their time. At the end of fieldwork, Gordon was still living on VAD support.

Jack, 27, took part in the interview with his fiancé Megan. Jack had been living with the VAD for 3 years. Jack had been fit and well until 2010 when he had experienced a heart attack and a stroke and was a member of the armed forces. Whilst living with the VAD Jack had experienced a serious bleed on the brain resulting in him being admitted to hospital. Jack was very keen for a heart transplant in the near future, as he was planning to get married, and have children in the near future. Jack has been transplanted since the interview was conducted.

Michael was 33 years of age, he was in an inpatient at the hospital at the time of the interview, he attended the interview with his wife and mother. Michael and his wife Kelly had a young daughter. Michael had not been placed on the heart transplant register since he had had the VAD implanted; the hope was that his heart would recover sufficiently for him to have the device removed and not need a transplant. Michael was extremely happy with the VAD and had not experienced any problems with the device since receiving it. At the end of fieldwork, Michael was still living with the VAD.

I have included details of the participant's marital status in the biographies above, as due to the level of care that is required whilst living with the VAD the recipient's social situation is an important consideration prior to implant. Whilst it is not necessarily required that the patient has a cohabiting partner, they must be deemed to have sufficient social networks

available to support them in the living with the device. Not all of the participants included in this study had partners, but those without partners had other individuals in their lives – parents or adult children- who could fulfil the care-giving role. However, as will be discussed in the empirical chapters the level of input that caregivers had on the management of the device varied significantly between interviewees.

I was engaged in fieldwork for around two years; at this point, I made the decision to stop interviewing. There were two primary reasons for this. Firstly, I felt that I had sufficient data to support the theoretical points that had emerged from the data. Secondly, time constraints of the PhD. After leaving the field, the clinical staff continued to update me, details of which are included in the participant biographies above.

The quotes selected from the interviews for inclusion in this thesis were chosen because I believed that they provided insight into the aspect of the experience that I was trying to elucidate. Although I have included quotes from all participants, some respondents have been quoted more than others.

4.2.3 Conducting the interviews

All interviewees were recruited from the same specialist centre, however they were widely dispersed geographically hailing from the North of England, Scotland and Northern Ireland. Interviewees were given the option of where the interview took place, whether they wished this to be at the hospital, their home, or another location of their choice. Allowing the participant to select the location of the interview was intended to reduce any imposition or inconvenience that might be incurred by taking part in the study. All interviewees opted to have the interview take place at the hospital. Some participants were inpatients at the time of the interview, but for the majority the interview was timed to coincide with a clinical appointment.

Where possible I arranged with the ward staff for a private clinic room to be available for the purpose of conducting the interview. Although such an approach was chosen for convenience, and privacy, it is acknowledged that conducting interviews within the clinical setting may pose some difficulties for interviewees in separating the researcher from the clinical team. The majority of those who were inpatients at the hospital were in private rooms, this facilitated the undertaking of the interview in a quiet and private environment. For those who were on a ward I presented the option of relocating to another room or quieter location. In the majority of cases, interviewees chose to relocate; only one interview was conducted on a ward. Whilst this was not the ideal environment for an interview, and had the potential to

limit the openness of the participants' responses, it was felt that it was not too detrimental and it was best to respect the preferences of the interviewees. Participants were also given the option of having a significant other be present in the interview. In interviews where partners were present, I found I was required to ask less questions as the VAD recipient and their partners would construct their story together and feed off each other's responses.

An interview schedule was developed to guide the interviews, this was a living document that was adapted and changed over the course of the study. As the interviews were semi-structured, the schedule was not prescriptive but rather acted as a guide for general issues to be explored. During the interviews I allowed myself to be guided by topics and issues discussed by the individual participants. There were several benefits to this flexible approach. Firstly, it allowed me to explore issues that were important to individual participants that may not have been anticipated in advance. Secondly, I believe this flexible approach allowed me to develop a greater rapport with the research participants than would have been possible following a prescriptive interview schedule. Finally, a flexible approach is often recommended for its potential for the uncovering of new lines of inquiry (Whyte, 1979). Phenomenological researchers have highlighted the importance of being open to whatever may be revealed during the interview, and maintaining this openness throughout the entire research process (Finlay, 2008). This openness is 'the mark of a true willingness to listen, see and understand. It involves respect and certain humility toward the phenomenon, as well as sensitivity and flexibility' (Dahlberg, Drew and Nystrom, 2001:97).

Interviews were initiated with the question 'Could you tell me a bit about the process by which you came to receive a VAD?' The intention of this approach was to elicit a brief synopsis of the individual's medical history that had culminated in the implantation of a VAD. This narrative approach afforded respondents the opportunity to give the history of their illness in their own words, focusing on particular events that were key to them. Such an approach is in line with the phenomenological basis of the study, which focuses on the lived experience of the individual (Finlay, 2008). Participants' stories often highlighted interesting issues that had not been anticipated, these were often explored with later questions. Responses to this question were varied; whilst some respondents were relatively brief, some spoke uninterrupted without the need for prompts for up to 10 minutes.

Interviews lasted between 40 minutes and 1 hour 45 minutes. After the interview, I often stayed for a brief informal chat to thank the respondents for their time and offer another opportunity to address any questions they might have.

Interviews were audio recorded with a digital recording device in order to maintain accuracy. Recording the interviews enabled me to maintain high fidelity without having to rely completely on field notes taken during the interviews themselves. However, field notes were produced for each interview. Field notes recorded pertinent details of the interview, any pre- or post-interview reflections as well as any key moments or responses from the participant during the interview. Field notes were written as soon as possible following the interview, the importance of avoiding delay in recording field notes has previously been highlighted (Lofland and Lofland, 1999). The field notes were utilised throughout the data analysis process, providing invaluable context to the interviews.

4.3 Personal factors of the researcher

It is important that I, as the researcher, locate myself in the research. Heidegger's phenomenology states that our consciousness is never free from our experiences; as such, my background is likely to have a significant impact on the data collected and the way it was analysed. When I began the fieldwork, I had no personal experience of VADs. My interest in the experience of VAD recipients stems from a wider interest in organ transplantation and its alternatives. I discuss below some reflections on the research and my potential impact on the findings.

Personal factors of the researcher may influence the type of data gained from participants as respondents form their own opinions about the researcher and research project (Burgess, 1984). Respondents may attempt to place the researcher in terms of age, race, class, and gender to establish the differences and similarities between them. I shared the same ethnicity as all my respondents. However, there was a difference in gender for all but three of the respondents and there was often an age difference. None of these differences between the participants and myself was felt to impede the data collection process. Different levels of rapport were established with individual participants; however, this was felt to be typical of interactions in daily life. Furthermore, one of the most difficult interviews in terms of rapport was with the participant closest in age to myself. The perceived awkwardness of this encounter may have arisen from difficulties of both the participant and myself in trying to establish our positions as interviewer and interviewee, our closeness in age and background highlighting the artificiality of the research setting.

Further, there were often issues regarding the participants attempt to place me, and my professional status. Throughout the fieldwork, I endeavoured to establish myself as separate from the clinical team. However, I felt that some respondents in particular, still associated me

with the hospital staff. Whilst this may have benefited me in gaining the confidence of some respondents, it may also have curtailed the responses of others who may have been reticent discussing negative aspects of their experience which could lead them to be perceived as ungrateful to the clinical team who had fitted them with the device.

The role of the researcher has been conceptualised as that of a 'sympathetic listener' (Finch, 1984). Although, this has been criticised by Cotterill and Letherby (1993) who suggest that many people have no requirement for the researcher to adopt this role, they have friends and family who fulfil these needs. On several occasions during the study, I felt that I was cast into this role. Respondents told me details of their experience that they expressed difficulty discussing with members of their family. Indeed, it has been suggested that respondents may feel more comfortable revealing feelings to a 'friendly stranger' than those closest to them as they are afforded anonymity (Letherby, 2003).

4.3.1 *Researching sensitive issues*

Due to the phenomenon of interest in this study, the experience of 'Being' a VAD recipient, it was acknowledged that emotionally sensitive topics, including death, would likely arise during the interviews. Discussing these issues could be potentially distressing to participants. To account for this potential distress, participants were advised that were not required to answer any questions that caused them discomfort, and they were free to withdraw from the study at any time without giving any reason. This approach was utilised to ensure that participants engaged only with topics with which they felt comfortable. However, it should be noted there is no universal agreement on what is considered a 'sensitive topic' (Renzetti and Lee, 1993). Responses to potentially 'sensitive' topics will vary between individuals, indeed this was observed amongst the respondents in this study.

During the interviews several of the respondents did become upset, this was something that initially caused me a degree of discomfort as I was unsure how to react. Over the course of the fieldwork, I learnt that the best way to manage these situations was to offer the participant a break from the interview, allowing them a moment to compose themselves if necessary. Following this, participants were often comfortable returning to the topic. A number of respondents expressed that they actually felt some benefit from telling the researcher their story. Potential benefits from participation in qualitative interviews have previously been suggested; these include catharsis, self-acknowledgement and a sense of purpose (Elmir et al. 2011; Hutchinson, Wilson and Wilson, 1994). However, I am not a trained counsellor and the interviews were conducted with the sole purpose of gathering data about the experience of

‘Being’ a VAD recipient. As such, I do not feel comfortable making any claims about benefits to the participant arising from this study, beyond extending the knowledge of ‘Being’ a VAD recipient.

Furthermore, it is important to note that the impact of discussing sensitive topics can extend beyond the participant to the researcher themselves (Lee and Lee, 2012). There is potential for vicarious traumatisation, whereby the researcher can experience second hand distress from respondents’ stories (Dunkley and Whelan, 2006; Schauben and Frazier, 1995). In order to minimise this distress, Fahie (2014) highlights the importance of ongoing supervisory support. Debriefing procedures involving the supervisory team were written into the protocol of this study, to minimise the emotional impact on the researcher.

Over the course of the interviews, I had emotional responses to many of my respondents’ stories. Further, I experienced grief upon learning that some of my interviewees had died. Although I had only the most minor role in my respondents’ lives, meeting them for a very brief period of time, I felt that these emotions were a natural response to my connection with these individuals. Emotion work is suggested to be an integral part of social research (Young and Lee, 1996), and as such, it should not be dismissed. Further, it is suggested that the emotion work extends beyond the fieldwork to data analysis and writing up (Hubbard, Backett-Milburn and Kemmer, 2001). Indeed, my emotional responses to participants’ stories were experienced not only during the interviews themselves but also throughout the whole research process, in particular when returning to the accounts of participants who were now deceased. I will now turn to this data analysis process, outlining the methods in detail.

4.4 Data analysis

The processes of interviewing, transcribing and analysing the data were conducted concurrently throughout the study; as such it seems somewhat incongruous to discuss data analysis as a distinct phase. However, for the purpose of achieving methodological clarity it is important that this process is documented.

The first stage of analysis involved familiarising myself with the data, each interview was transcribed verbatim by myself. This involved repeatedly listening to the recordings which, although time consuming, enabled me to become immersed in the data. I also turned to my field notes which Morgan (1997) positions as a ‘step toward data analysis’ (ibid.: 57-58).

The second stage of analysis was to turn to each transcript individually. Two approaches have been outlined for the purpose of uncovering thematic aspects of a phenomenon: highlighting and line-by-line coding (Van Manen, 1984). These two approaches serve different functions

in the search for meaning, and we ask different questions of the data during each. During highlighting, we ask ‘what statements or phrases seem particularly essential or revealing about the experience being described?’ and when engaged in line-by-line coding we interrogate every sentence, asking what it reveals about the experience of interest. The search for meaning is expedited by the use of both these approaches. Transcripts were initially analysed line by line. This involved close reading whilst attributing a code to each segment of text. This could be a word, a line or a chunk of text, and each segment could have more than one code attributed to it. As the analysis went on there was a tendency to adopt a highlighting approach. An example of a transcript coded in the initial rounds of analysis is provided in Table 3.

Table 3: Example of a coded interview transcript

Transcript	Codes
Jan: A patient will say ‘ohh, well I don’t know’ I say ‘well, you either do or you die, but it’s up to you at the end of the day no matter what I say’.	Lack of choice
Terry: They don’t give them away; they’re not offered one because you know.	Perceived need for the device
Jan: Because they’re fashionable. I tell it as it is you know, either you want it or you don’t. If you want to die, lie down somewhere and get on with it, you know what I mean. I won’t and I’ll take a few with me. But we’ve, I’ve lost a lot a lot of friends along the way.	Mutually constituted story VAD community
Terry: Yeah we’ve lost a lot of people, a lot of people.	Switch from ‘I’ to ‘we’, repetition
Jan: A lot of close people.	Upgrade, not just people, close people

Themes began to emerge from the data following early analysis; however, these were constantly subject to change as the process of data collection and analysis continued. Themes underwent several rounds of evolution before settling on those included in the study, and at various time points these were mapped and rearranged. A cyclical approach such as this is recommended for qualitative research, as the purpose of the investigation is to understand rather than predict the phenomenon of interest (Westbrook, 1994). In addition to revisiting themes, each transcript was re-examined in light of subsequent interviews. Although this

study did not use a grounded theory approach, this fits in line with the iterative elements of ‘constant comparative analysis’ (Glaser and Strauss, 1967). I returned to my reflective journal throughout the process of data analysis, this allowed me to reflect on emerging themes against fieldnotes from the interviews.

As key themes began to emerge from the data, a codebook was developed, this comprised of separate tables for each theme, an example of this is provided in Table 4.

Table 4: Example of a theme table for VAD communities from the code book

VAD communities	
Experiential knowledge	<p>‘When I came in for assessment there was a lady in...who’d had the VAD for about six months who was very kind and came and talked to me about it and showed me the whole thing...she’d had a fairly horrific experience as many of them as many of the people who’ve got VADs had where she’d ended up really being put in a position where it was you have it or you die, she’d previously didn’t, hadn’t wanted to have it done, but she’d ended up in ITU...and she’s gone from there to saying how relieved she was that she’s had it done and how she wished she’d had it done you know years before really, and she was clearly very healthy...her view was you know don’t even think about this it’s not even going to be a problem for you and she’s right ha so yeah’ (James, interview 1)</p> <p>It’s one thing speaking to you, know like a psychologist, or you know someone like you, or you know a doctor or nurse, but I found it a lot better talking to someone whose actually been there and done that, whose actually gone through the experience themselves. (Jack, interview 19)</p>

Writing formed a major component of the data analysis process, in line with the teachings of Van Manen (1984). The process of writing facilitates the uncovering of essences of the phenomena through engagement with the hermeneutic cycle. This involved a cyclical process of reading, reflective writing and interpretation (Laverty, 2003). Engaging in reflective

writing and rewriting allows us to try and capture the complexity and ambiguity of the lived world being described (Finlay, 2008). Figure 11 demonstrates this process.

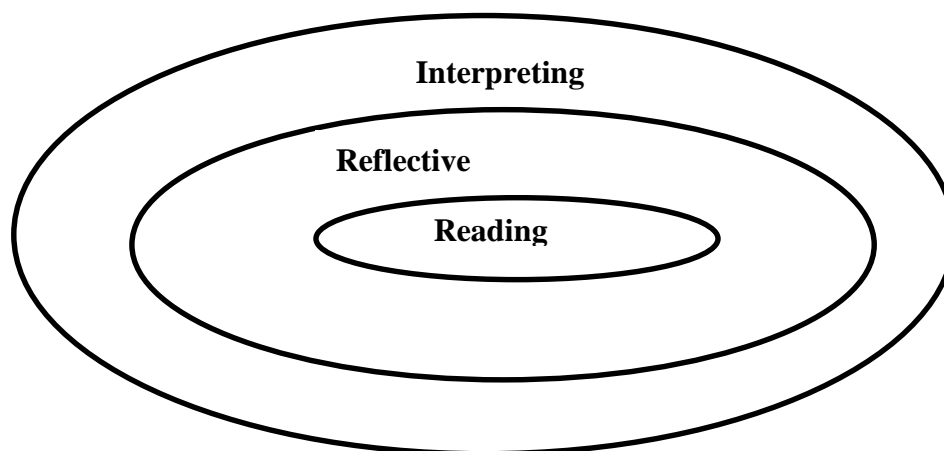


Figure 11: The Hermeneutic Cycle (Kafle, 2011)

The reflective journal I kept throughout the research project afforded me an informal outlet to engage in this writing process. This process of writing and rewriting continued throughout the data analysis process, until it was felt that the themes provided an account of the essence of what it means to 'Be' a VAD recipient.

4.4.1 *Quality control*

Whilst qualitative research does not subscribe to the same quality control measures as quantitative methods, these should be an integral and explicit part of qualitative research (Bergman and Coxon, 2005). Further, Kafle (2011) highlights the importance of maintaining quality throughout the research project as a crucial aspect of interpretive phenomenology. One aspect of this quality is the trustworthiness of the findings. The following steps were taken in order to establish the credibility of the findings.

During data analysis a process of peer debriefing was used to review emerging themes; this took two forms. Firstly, during the data collection and analysis I was engaged in a qualitative data analysis study group that met fortnightly. This involved sharing anonymised transcripts, focusing on specific segments. As a group, we shared interpretations of the data; this afforded the opportunity for me to question and review themes. Secondly, my supervisory team were engaged in analysis of the data; at regular meetings segments of transcripts, full transcripts or analytic writing, were shared. This process continued throughout the entire study. Again, this facilitated the testing of themes. This approach is supported by Lincoln and Guba (1985) who

suggest that engagement in peer debriefing is a useful means of establishing the credibility of a study.

Although I did not engage in member checking (Lincoln and Guba, 1985), findings of the study were fed back to clinicians. Following the completion of data collection, a feedback session was arranged with key clinicians who had acted as gatekeepers for the study. The purpose of this was to establish whether the findings of the study were consistent with the clinicians own experiences of working this group. In the absence of member checking, it was felt that this approach would be beneficial for the credibility of the study.

Throughout the study, the researcher adopted a reflexive attitude. This is the process of validating the research practices by reflecting how data collection and analysis may be affected by one's own action, values, and perceptions (Gerrish and Lacey, 2006). Whilst this process is important to establishing a strong and trustworthy inquiry (Lambert, Jomeen and McSherry, 2010), it is also an essential component of an interpretive phenomenological stance. However, Finlay (2012) highlights the need to be aware of the danger of falling prey to navel gazing in the process of researcher reflexivity. There is a risk of privileging the researcher over the participant, and Finlay (2012) emphasises the need for focus to remain on the research participant and the phenomenon in its appearing. As such, the themes arising from the data were constantly subjected to questioning as to what unique insight they provided about the experience of what it means to 'Be' a VAD recipient.

4.5 Conclusion

By dividing the methods and methodology into two chapters, I have been able to explore theoretical and methodological issues in greater detail. In chapter 3, I outlined the methodological approach employed in this study. Whereas in this chapter, I have focused on the actual research process, and some of the personal and practical issues than have arisen in the undertaking of this study.

As the aim of this study is to understand the experience of 'Being' a VAD recipient, an interpretive phenomenological approach has been adopted as the theoretical basis for this study. These two chapters have outlined the justification for this approach and the manner in which it informed the undertaking of the study.

In this chapter, I have also explored issues concerning my own role within the research process. I believe that it is important for me to outline these influences both from an ethical perspective and in terms of the trustworthiness of the data. Firstly, as I have adopted an interpretive phenomenological approach it is acknowledged that the following discussions of

what it means to 'Be' a VAD recipient are influenced by my own interpretations as well as those of the researcher participants. It is not possible to produce a pure description. Secondly, my personal characteristics may have influenced my relationship with respondents and the data that was collected from them.

The following chapters outline some of the findings from this study in an attempt to establish what it means to 'Be' a VAD recipient.

5

Receiving the VAD

Chapter 5. Receiving the VAD

5.1 Introduction

This chapter focuses on the experience of receiving a VAD in chronological order in order to provide as full an account of this experience as possible, highlighting the key issues at each juncture in the process. The chapter begins with a discussion of the initial offer of the VAD, how it is presented by clinicians and the manner in which potential recipients respond to it. Such responses include: the perception that the VAD is a confirmation of the severity of their illness and vulnerable grasp on mortality, or relief and gratitude that recourse is still available for their condition. The chapter then describes the process and factors involved in deciding to have the VAD implanted, outlining respondents' concerns about accepting the VAD into their body, mixing the 'self' and 'not self'. Key to the decision making process appeared to be the notion of 'not having a choice'. Thirdly, this chapter discusses the respondents' personal narratives of having the VAD implanted, in particular highlighting the potentially distressing experience of the intensive care unit. Attention is then turned to the initial period of life attached to the VAD and how respondents orientate to the workings of the device and how personification is used to reduce the 'otherness' of the VAD. Finally, the chapter discusses how respondents reflect back on the experience of receiving the device as a time of great stress.

5.2 The offer of the VAD

As VADs are offered as a BTT, to those thought to be too weak to survive until a donor heart becomes available, the offer of the VAD could be viewed by potential recipients as confirmation of the severity of their condition. They are being offered the device because they are on the verge of death. During the interviews, it became evident that there were differences in the histories of heart failure of those offered VADs; some had been living with the condition for years or even decades where others had only recently received a diagnosis following an acute cardiac event. Amongst the interviewees without a history of heart failure, the suggestion of VAD implantation was often met by shock and disbelief at the severity of their situation.

It was quite a lot to take in at first...almost like a hammer to the face...it did take us quite a while to get used to...I noticed you kind of get the feeling that you're not going to get any better, I know it sounds strange, but it was almost within a couple of hours...I was thinking 'Ohh, God I do need it', and it was almost immediately after that I knew I need to have this done.

(Jack, BTT following an acute event, 3 years on VAD support)

Jack was a young, physically active man, and member of the armed forces. The idea that he could be dying of heart failure and require what is essentially a life support device was incongruent with his view of himself. Jack's comparison to being stuck in the face with a hammer highlights the hard, unpleasant shock of the realisation of his illness. However, in spite of this shock Jack said he was able to accept his situation, and his need for the VAD, quickly. Jack demonstrates a level of trust and acceptance of the advice given by the clinicians; if they say he needs a VAD, then he does. Similarly, Albert highlights the shock he experienced in learning that not only was he seriously ill, but also required a piece of technology in order to survive.

Before that [the heart attack] I was on Ramipril [blood pressure medication], blood pressure was controlled, I was on regular blood pressure checks at the Doctors with no problems at all, I was fit, I was still doing a lot of exercise, including circuit training with international level athletes so I was fit...I was fit, strong and I thought healthy. (*Albert, BTT following an acute event, 1 ½ years on VAD support*)

Being fit and healthy had been a key aspect of Albert's personhood. Not only was Albert fit, he was training with international level athletes. Albert had felt that he was healthy and nothing had been identified by his doctors that indicated differently. Needing the VAD was at odds with Albert's view of himself; it disrupted important aspects of his self-image. For both Jack and Albert, the experience of being diagnosed with advanced heart failure and being told of the need for a VAD could be considered a form of biographical disruption (Bury, 1982). The theory of biographical disruption assumes that there is a 'natural order' to our lives, and this may be disrupted by the development of a chronic illness (ibid.).

For those who had an established history of heart failure, the offer of the VAD appeared to be experienced slightly differently. Like those with an acute event, the VAD was similarly met with fear, but this was mediated by feelings of relief and gratitude.

I was scared, I mean it's a very frightening thing to compute really...someone is going to open your chest...so yes, I was scared but I felt so ill that I was just relieved that something could be done, because I was at the point where my life was really terrible. (*James, BTT following chronic heart failure, 11 months on VAD support*)

James demonstrates an awareness of the major operation involved in implanting a VAD. However, any fear at the prospect of this is outweighed by his gratitude at having a treatment

option available to him. Prior to the offer of the VAD, James had been informed that he required a heart transplant but any heart he received would fail because he was suffering from pulmonary hypertension. For many of those with a history of heart failure, like James, the offer of the VAD was in response to deterioration in their condition. Thus for these individuals the offer of a VAD is an offer of hope, for a longer life, for a better quality of life and for a chance of a heart transplant in the future.

For many of the interlocutors, the time when the VAD was offered was characterised by an increased sense of awareness of their own mortality. Heidegger states that the certainty of death is the fundamental confirmation of our existence in the world (Heidegger, 1985). As such, we all possess awareness that we will one day die, but for the most part this is an abstract concept, something to be dealt with at some uncertain point in the future, not something that in the main we consciously need to deal with on a daily basis (Little et al. 1998)⁴. Indeed, it has been suggested that the desire to keep awareness of one's mortality subliminal is a device for coping with the human condition (Frommer, 2005). However, certain life events, such as illness can cause our bodily functions to become transparent, allowing thoughts of death to intrude into our consciousness. Indeed, in Bury's (1982) theory of biographical disruption he makes the comparison between chronic illness and war, both have the capacity to bring thoughts of death into our forethoughts. For the respondents in this study death was increasingly becoming a feature in the horizon of their day-to-day lives.

Basically at the time they put the pump [VAD] in I had probably got 4-5 weeks left. And I felt like I'd got 4-5 weeks left. It's the only time I've really felt like I was going to die...you know you're dying but there's a difference between knowing you're dying and knowing you've got a set time left. (*Fred, BTT following long history of heart failure, 3 years on VAD support*)

The time preceding the VAD implantation, was for Fred, one of extreme illness and an acute awareness of the closeness of death. Indeed, this awareness had become so acute he felt like he had a specific amount of time left, a matter of weeks. Fred's belief of having a set amount of time left to live is reminiscent of death's hourglass, which gives physical manifestation to one's lifetime as something, ticking, flowing, or trickling away. Whilst, Fred had been living

⁴ Obviously, there are exceptions to this, those who choose to dwell upon death. However, we might categorise these individuals as being overly morbid, or in extreme cases psychologically disturbed, or part of a (religious) system of thought and practice, in the case of some forms of Buddhist meditation, and not representative of the general populace.

with heart failure for a number of years, only recently had he been confronted with death as a very real and close possibility. For those in situations like Fred where death is seen as rapidly approaching the VAD has a dual identity, it is both a confirmation of their dire situation and also a lifeline, an opportunity to give oneself more time. Indeed, for many of the interviewees the VAD was seen as a last chance.

5.3 Decision making

Following the offer of the VAD, the majority⁵ of respondents had to make the decision of whether or not to have the device implanted. This section will consider how respondents in this study viewed this decision making process and their considerations in deciding whether or not to have the device.

One such consideration was the issue of integrating a piece of technology into the body.

It is in moments of illness that we are compelled to recognize that we live not alone, but chained to a creature of a different kingdom, whole worlds apart, who has no knowledge of us and by whom it is impossible to make ourselves understood: our body. (Proust, 1925: 304)

Technology is a vitally important aspect of our lives, technologies are evident in every facet of our lives; they feed, clothe, and provide shelter for us; they are woven inextricably into the fabric of our lives, stretching from birth to death. Whilst we engage with technologies everyday of our lives, the majority of the time we take them for granted.

However, our reliance on technology becomes more apparent when we are fitted with medical devices, such as VADs, that are essentially keeping us alive. Medical technologies are increasingly being used to treat illness and disease. In particular, medical devices are playing an ever more important role in the treatment of heart disease, with the rise in the use of ICDs, pacemakers and VADs. The relationships we have with these medical devices go beyond the everyday relations with technology that have become a normal aspect of our lives. These technologies offer unprecedented control over the human body, but may also compel a crisis over what the body is and what it may become (Williams, 1997). Jackson (2002) suggests that such intimate relationships with technology can prove problematic:

⁵ Some of the interviewees were in a critical condition when they received the device and as such did not actively make a decision to have the device. This section will focus on those that were actively involved in the decision making process.

It can be difficult for human beings to entertain or tolerate an intimate, intercorporeal relationship with the world they think of as not-self. But when one's life depends on entering into such a relationship people have recourse of strategies of reciprocity in order to make the relationship viable. (340)

For the respondents in this study, life following the implantation of a VAD becomes intimately linked with technology. Recipients of VADs must learn to become essentially dependent upon the device to live, and accept the technology as something that is intimately connected to them. Difficulty contemplating the prospect and implication of joining technology in their lives in this manner, where the 'not-self' intimately entangles with the 'self', was a factor in deciding whether to have the VAD implanted or not. One facet of this was the trustworthiness of the 'not-self'.

HS: What was it that put you off [having the VAD], was it the risk involved in the operation?

April: I think the risk was a big factor, even though you know it's quite safe to go through that, but it was the after thoughts as well, in thinking what if something goes wrong, you're suddenly relying on a machine in a way to live...*(April, BTT following long history of heart failure, 3 years on VAD support)*

We are all aware that technologies are fallible. Electronic devices and machines fail, we all have experiences of malfunctioning cars and misbehaving computers. Although we put our lives in the hands of technology on a daily basis, for instance when driving or travelling by plane or train, this trust in machinery is not something that we routinely consciously consider. This reliance becomes more apparent for those fitted with medical technologies, such as VADs, to keep them alive.

In addition, misunderstandings about the nature of the VAD caused some interviewees to dismiss the idea initially. As outlined in the introduction, there are two different types of VADs and some respondents initially believed they were being offered a paracorporeal device such as the Berlin Heart®. For many the Berlin Heart® was viewed as an object of fear, and something that was rejected off hand.

Well the Berlin, I just wouldn't entertain it. I can tell you that, I put me hand on me heart and say I've seen these little kids with them in [Berlin Heart®] and it's unbelievable how resilient kids are, I mean I'm a 55 year old, I've

done a lot in my life, I've had a good life I could of went 'well just let us go' as long as I didn't suffer, just let us drift off it wouldn't have bothered me, I couldn't, I just couldn't have coped with that not the type of lifestyle I've lived and the type of things what I like doing, the Berlin heart wouldn't allow us to do them, whereas this to some extent lets us do quite a bit, well 90% of what I could do and that so it's...Big machines and human beings don't mix, the littler the machine the better and this isn't little, but it's little enough to live a normal life. (*Gary, BTT following a long history of heart failure, 2 years on VAD support*)

To Gary, the unacceptability of the Berlin Heart® was so extreme he would be prepared to let himself die rather than face the limitations that it would have imposed on his life. Whether Gary would hold this position if the decision he was being faced with was a Berlin Heart® or death is beyond our reasoning. Gary's description of the VAD being 'little enough to live a normal life' is particularly interesting. For Gary, in order for an entwining of the body and technology to be acceptable, the 'not-self' cannot overwhelm his self. Gary's reasoning appears to be focused around maintaining an acceptable level of functioning, suggesting that there is a balance to be achieved between health outcomes and the impact on the individual's life. The acceptability of medical treatments is important, people will not blindly accept something if they do not perceive that it fits with their lives and values. This has also been demonstrated amongst those with other conditions, for example in patients with sleep apnoea, certain treatments, such as tracheostomy, may be rejected because they are considered unacceptable (Moreira, 2006). It appears that in order to a treatment to be acceptable, a balance must be achieved between the limitations imposed by the treatment and the therapeutic effect.

One approach used by the respondents to help them to decide whether to have a VAD, or not, was to seek out as much information as possible about how the VAD worked.

Ian: I'm an engineer you see, see this pump, I know exactly how it works from start to finish, I probably know better than a lot of people, the amount that I've looked into it. I've looked into the company's website and got all the information from them, understanding exactly how the device works itself...

Lyn [Ian's wife]: I don't know whether that's a good thing or a bad thing sometimes, you can kind of know too much.

Ian: No, not really. I think it's better to know what you're dealing with. (*Ian, BTT following a long history of heart failure, 7 months on VAD support*)

Ian and his wife Lyn often expressed differing opinions during the interview; this was often focused in particular around the amount of information they desired about the VAD. For Ian, learning as much information as possible about the mechanical workings of the VAD was an important step in accepting the implantation of technology into the body. Learning about the working of the VAD helped in understanding the need for a VAD, and what benefit it would bring. It was a useful tool in making sense of the new body to be, the 'mix' of the 'not-self' and self.

For some of the respondents, the offer of the VAD was not the first time they had been faced with the idea of mixing the self with the 'not-self', as they had previous experience of living with other medical technologies such as ICDs⁶.

Matt: I've had me dfib [ICD] turned off now because I was getting shocked and I was still in VT [Ventricular Tachycardia⁷], although I've told em to turn it off. But the only problem now is I don't know if I'm in VT, cos I've no heartbeat. So, I don't know. So I feel a lot happier now I've had it turned off.

Susie [Matt's wife]: I think both of us do actually. Cos it, I mean when it [ICD] fired, n it fired three times didn't it, that morning when we were in bed? And you automatically grabbed hold of me, so it took me about a year for me to actually be able to sleep facing him...because of the fear of his dfib going off...and him punching me in the head you know and I'd rather him punch me in't back of head instead of me face so it took me about a year before I could actually physically sleep facing him. Cos I couldn't, just couldn't do it. Erm but no. He sleeps in't middle of us, doesn't he? (*Matt, and his wife and Susie, BTT following long history of heart failure, 2 ½ years on VAD support*)

During the interview, Matt compared his experiences of the ICD and the VAD. The impact of the ICD on Matt's life had been mainly negative. This was primarily due to the unpredictability of the defibrillating aspect of the device, which had discharged

⁶ ICD's are implantable heart devices used in patients at risk of sudden cardiac death from abnormal heart rhythms.

⁷ A type of abnormal heart rhythm that causes the heart to beat too fast.

inappropriately on several occasions. The ICD was a source of emotional stress to both Matt and his wife; it interfered with basic aspects of their relationship, like the ability to share a bed. Matt's different reactions to these two heart devices suggest that there is an inherent difference between them. Whilst the VAD might hold a greater presence in the recipients' everyday life, it is generally predictable in its functioning, and therefore to Matt and Susie is experienced as more acceptable, hence the device is allowed to sleep in the middle. In addition, Susie's reference to the device as a 'he' indicates that they have anthropomorphised the bag, this may be a way of helping them make sense of the device and its permeant presence in their life.

5.3.1 Hobson's choice⁸

Due to the nature of their illness, some interviewees had longer to consider the possibility of the VAD than others. For many those with a history of heart failure the possibility of fitting a VAD had been discussed prior to them being in a critical condition. However, extra time to consider the VAD did not necessarily aid the decision making process. April described her inability to personally make the decision of whether or not to have the device.

I spoke to George [transplant co-ordinator] about getting an LVAD fitted, but I could never make the decision, I never actually felt poorly enough...and then I was told the decision was taken from us, I had to have a VAD or I just wouldn't be here now. *(April BTT following long history of heart failure, 3 years on VAD support)*

April's reference to not feeling 'poorly enough' suggests that she felt she needed to reach a threshold of illness before she could accept the VAD, which she did not perceive that she had achieved. April states that eventually the decision was taken from her. However, a decision still exists. Whilst April might no longer have the luxury of a choice of treatment options, there is still a choice of whether or not she wishes to have the treatment at all. April retained the autonomy to say 'yes' or 'no'. Whilst it might be recommended by clinicians, April, and any of the respondents, could have refused the VAD if they wished. April's reluctance to make the decision about whether or not to have the VAD could have been because she was unaware of the grave reality of her situation or was reluctant to confront it. Furthermore, April's reluctance may demonstrate a desire to retain some options for her future. If for any

⁸ Hobson's choice is a free choice in which only one option is offered. The saying is thought to originate with Thomas Hobson (1544-1631) a livery stable owner in Cambridge who, in order to rotate his horses, would offer his customers the choice of the horse in the nearest stall or none at all. Hobson's choice is a choice between something and nothing.

reason the VAD was unsuccessful, April's future treatment options are severely limited, heart transplantation is the only other option. By holding off the decision to have the VAD or even the transplant, for as long as possible she is able to retain some options.

Due to the unpredictable and highly changeable nature of heart failure as a condition the manner in which the VAD is presented could change within a short period of time.

From the May, Matt was quite a fit and active person...in the next sort of space of the next three month it was very much a very, very rapid decline, so from us being told 'yeah, you need a transplant' and they might possibility fit a VAD, that was the August time, to the October time when it were like you've got no choice you have to do it, it was a very, very quick, you need it or that's it really. *(Susie, wife of Matt BTT following long history of heart failure, 2 ½ years on VAD support)*

The two time points Susie refers to above were only three months apart, highlighting the unpredictability of the heart failure trajectory. During this time, the VAD had changed from being a possibility to a necessity. For many respondents a period of rapid decline in their condition led them to feel that their options were running out. This often resulted in the perception that there was not a choice to be made about whether to have the VAD or not.

There was never, ever 'you can have a heart transplant, or you can have the VAD'. It was more the case of you have the VAD you'll be alright, you don't have the VAD you're going to die. It was Hobson's choice really. *(Gary, BTT following chronic heart failure, 2 years on VAD support)*

Hobson's choice appears to be a pertinent analogy for the reality for these individuals. Their choice is to say 'yes' to the VAD, and as such the chance at life, or 'no' and therefore risk imminent death. The concept of Hobson's choice has previously been applied to the experience of individuals on dialysis (Fetherstonhaugh, 2007). In her study, patients with end stage renal failure did not actively want or choose dialysis, however, it was the only alternative to an otherwise certain death, their choice was dialysis or death. Similarly, respondents in this study had chosen not to die, and as such the VAD became the inevitable, and only, recourse. Many of the interviewees recognised the stark reality of their decision.

They [clinicians] said 'we can do you on a VAD, do you want one?' and I went 'not really, no', and then in the end you go 'well, what's the alternative?' Alternative a) have a VAD, b) die. Have a VAD or die? Have a

VAD or die? Ohh go on I'll have a VAD. (*Simon, BTT following chronic heart failure, 1 ¾ years on VAD support*)

The VAD, as Simon recognises, it is not something that anyone would actively want or choose to have, however in the face of no other options it is accepted. Similarities can be drawn to the choice faced by those with breast cancer requiring a mastectomy. Whilst a mastectomy may be lifesaving, it has far-reaching consequences for the experience of body and identity (Piot-Ziegler et al. 2010). Undeniably the VAD, whilst potentially lifesaving, also has far reaching impacts on the recipients life and body.

Decision-making about whether or not to have a VAD involves consideration of several factors, including the nature of the VAD as a piece of medical technology, as a 'not-self', and the impact it would have on their lives. However, there was a strong sense they were being offered a choice between something and nothing, there was not really a decision to be made, unless they wanted to die, the VAD was the only option available to them and as such they would accept it.

5.4 Implantation experiences

The implantation procedure for a VAD involves open-heart surgery, similar to that required for heart transplantation (British Heart Foundation, 2015d). Such invasive surgery carries with it an extensive rehabilitation process. This generally involves a stay in intensive care, followed by the high dependency ward and finally a period of time in a cardiothoracic surgical ward, before the individual can be discharged home. The journey from implantation to discharge typically takes around 4 weeks, although this can vary between patients (National Heart, Lung and Blood Institute, 2012). During the interviews, many respondents touched upon their experiences of having the VAD implanted. In particular, the period of time spent in intensive care (ICU) appeared to have the biggest impact on respondents in this study. Understandably, recuperation from a major operation like VAD implantation is going to be a difficult process. These difficulties appeared to be further compounded by the unpleasant experience of being in intensive care.

At the end of the day it's not exactly a bowl of cherries having your chest cracked open and being in intensive care, not being able to eat and just completely reliant on other people, you're out of control and I mean intensive care they're basically torturing you...I've seen a side of myself when I was in there which I didn't realise I had, and I mean my wife has never ever heard us shout, lost me temper in 20 odd years of marriage...swap places and see what it's like because it's not nice but it's a small price to pay, that one week. (*Gary, BTT following chronic heart failure, 2 years on VAD support*)

The stay in intensive care following the VAD operation appeared to be marked by a sense of helplessness, where control over one's body and its care is completely relinquished. During this period the patient's body is no longer their own as they are 'at the mercy' of the medical staff. Russell (1999) has previously noted the issue of power relations in intensive care, in her exploration of patient's memories and experiences. Many of her respondents referenced memories of being held down, restrained or medicated 'into oblivion'. The experience of intensive care on Gary was so profound he (and his wife) discovered a different and negative side of his self. However, in spite of the unpleasantness of this experience, he views it as ultimately being worth it for the positive benefits received from the VAD.

The power of ICU to bring forth facets of the self that the individual was neither aware, nor particularly proud of, was evident in the accounts of several respondents.

I had to spend a lot of time on ICU [intensive care unit] afterwards...and I was the only, practically the only patient that was conscious, throughout the whole thing. And you see a lot on that ward, made me very angry...I've always been so easy going and I was so easy wound up. But it was just because some of the sights that you see and that's happening three feet away from you, you know just the other side of the curtain you can hear everything, every single thing that's going on, you can practically see everything that's going on, you know it's not pleasant. (*Ian, BTT following chronic heart failure, 7 months on VAD support*)

Ian describes his distress at being exposed to the other patients and occurrences of ICU. Ian's stay in ICU was extended beyond that of most of the interviewees; this was due to complications with his condition that required him to have continuous veno-venous

haemofiltration⁹, which was only available within the intensive care department of the hospital. During this time Ian was highly conscious and aware of his surroundings, more so than many of those on ICU. Ian refers to the disturbing sights and sounds of ICU, which patients and families have previously compared to war zones, factories and being out in space (Russell, 1999). The experience of ICU appears to differ from the general experience of being in hospital, and it was something that remained in their consciousness for some time afterwards. Furthermore, the thought of Ian having to negotiate the ICU experience again was one of his wife Lyn's major fears regarding the prospect of a heart transplant, demonstrating that its impacts go beyond the patient to family members. This idea is supported by previous research that has found high incidences of psychological distress amongst relatives of ICU patients (Jones et al. 2004).

The most extreme account of ICU came from Albert, who reported experiencing distressing hallucinations.

I came round, and at the time I was hallucinating, I thought all the nurses were trying to kill me. In particular one, who said she wanted to take me temperature, but I could see this shell she had, she was gonna poke in me ear and scoop me brains out. Totally hallucinatory of course, and gradually that faded away, I was in ICU for quite a long time. (*Albert, BTT following an acute cardiac event, 1 ½ years on VAD support*)

Albert reflects on these memories in a very pragmatic manner, dismissing them as hallucinations, however the distress that these must have caused at the time cannot be underestimated. Albert spent a considerable amount of time in intensive care before, and after, the VAD implantation. Drifting in and out of consciousness, undergoing a number of procedures including the VAD implantation, the majority of which he lacked the capacity to consent to himself. Dreams and hallucinations have been reported in studies of intensive care patients six months post discharge (Adamson et al. 2004).

It was during this time spent in intensive care that respondents first began to process the changes to their body conferred by the VAD. A crucial step for respondents in the process of making sense of this merging of technology with the body and the acceptance of the 'not-self into the body was getting used to the external peripherals of the device and that fact that they are permanently attached to you, and that your body now extends beyond the traditional

⁹ Veno-venous haemofiltration a type of dialysis used for acute renal failure for patients who are unable to tolerate haemodialysis.

boundaries. Previous research has conceptualised time spent in ICU as a period of technological dependence (Cutler, Hayter and Ryan, 2013). Indeed the respondents described how they were fitted with various pieces of medical equipment; these were often muddled with the external components of the VAD. This could cause difficulty in comprehending exactly what the VAD entailed.

As soon as like anaesthetic and that wears off, and you stop being a bit daft, it's like 'arghh' you think 'ohh, what's happening?' and obviously I thought when I first seen this [VAD driveline], I just thought it was a drip. 'cos obviously I remember seeing the videos and all that, but I didn't know what it was gonna look like, and then I sort of sussed it, like obviously when the drips went I'd still got this [VAD driveline] 'n thought 'when's this going? Ohh that's the VAD'. (Ben, BTT following an acute cardiac event, 2 years on VAD support)

Like Ben, several respondents reported how they expected the external components of the VAD to be removed along with the other medical equipment. The realisation that these external components were actually permanently connected to them occurred over time. These experiences suggest a potential difficulty in aligning what is known about the VAD prior to implantation with the reality of the device.

The period of time spent in intensive care following VAD implantation appeared to be a particularly distressing aspect of the experience for many of the respondents. This distress took several levels that included: a loss of control over one's own body, exposure to upsetting sights and sounds and psychological disturbances. However, intensive care is by no means the end of the journey for VAD recipients.

5.5 Beginning a 'new' life with the device

Following discharge from hospital, individuals must begin the process of adapting to their new life with the VAD. This includes learning to fit the device around their day-to-day lives or conversely, fitting their day-to-day lives around the VAD. The majority of respondents were discharged home after several weeks recuperating in hospital, following discharge they are largely responsible for caring for the device themselves. To prepare for this they are intensively tutored in how to look after the device and its external peripherals. Discharge was the starting point for acceptance of the device and the reality of its prominence in their lives for the foreseeable future. Reliance on a life support machine to live, is not something that respondents would have anticipated in their lives, nor is it something of which they have any

experience. Whilst the majority had experience of managing their illness with medication regimens, this is quite different to having one's life intimately tied to a piece of technology. Furthermore, the VAD requires work on the part of the recipient to manage the device; they must become comfortable with the intimate working of the device and gain confidence in its management before they can be discharged from hospital. This care giving involves changing batteries every 4-8 hours, and changing the controller when necessary. The majority of respondents had never actually experienced a controller failure; however, it was something that they need to be completely prepared for.

What I couldn't get round was when you had to change your controller... 'cos I'm thinking 'well that's pumping my heart, if I unplug it my hearts not [working]' he [George, transplant coordinator] said 'no, your heart still works, and if it does fail you'll just go back to how you were before we fitted it'...once you've got your head around that I thought 'Yeah, I can unplug this no problem'. (*Stephan, BTT following chronic heart failure, 11 months on VAD support*)

Many respondents experienced initial difficulties in making sense of the device and how it worked. This included the need to establish a coherence between the practices of living with and caring for the self and 'non-self'. For Stephan, discussions with the specialist nurses were vital in becoming comfortable and confident in dealing with the device.

Another factor in integrating the 'not-self' was to normalise the experience of being attached to the VAD and develop a successful 'relationship' with the device.

Eventually I got home and...everything has been fine, and [I] got used to the idea, because it was a bit of a shock to the system at the beginning, got used to it [and] thought 'well it's my new best friend it's going to go everywhere I go'. (*Stephan, BTT following chronic heart failure 11 months on VAD support*)

Viewing the VAD as 'your new best friend' was a method employed by many of the respondents in accepting the device into their life. Others went a step further, personifying the 'not-self', describing how they had given the VAD with a name:

Marvin, we call him Marvin, his name's Marvin...it has to have a name because it's part of you really in't it. (*Jan, BTT following chronic heart failure, 4 years on VAD support*)

Giving the VAD a name and attributing human characteristics may have been a means of breaking down the otherness of the device, and reforming the ‘not-self’ as self, albeit in some ways a separate self. This facilitated the development of an intimate relationship with the device. Naming the device and talking about it as if it has life of its own can be seen as a form of anthropomorphism¹⁰. Devereux (1967) suggests that we experience trauma when exposed to unresponsive matter, and attaching anthropomorphic traits may help us in dealing with this trauma. Furthermore, it has been suggested that anthropomorphism is a psychological consequence of an emotional response to the machine as an extension of the body (Weizenbaum, 1976). Similar behaviours have been observed amongst recipients of organ transplants, who give the organ a name in an attempt to personalise it (Forsberg, Bäckman and Spencer, 2000).

5.6 The receding spectre of death

As discussed earlier, recipients experiences leading up to VAD implantation are marked with an awareness of death as a very real threat and something that is present to hand. Conversely, in the time immediately following implantation this threat begins to reduce and become more transparent. The interviewees described a how death began to recede from being a feature of their day-to-day consciousness.

I feel like I’m not dying ... and that was the thing, I think that’s when it sunk home, that yes I am ill, but I’m not dying. (*Fred, BTT following chronic heart failure, 3 years on VAD support*)

Fred highlights an important distinction between feeling ill and feeling like one is dying. Following the implantation of the VAD the recipients’ status has changed, whilst they are no longer dying they are still not well, they lie somewhere in between. This ‘in-betweenness’ can lead us to consider the position of the VAD recipient as liminal. Liminality is an ambiguous state that occurs when individuals have been stripped of their previously held social status without having yet transitioned to a new one (Turner, 1969). It is a time of flux. The concept of liminality and conceptualisation of VAD recipients as liminal entities will be drawn upon throughout this thesis. Furthermore, whilst the improvements in functioning conferred by the VAD may lead to the awareness of death receding from day-to-day consciousness, in that the

¹⁰ Anthropomorphism is the attribution of the human form or human characteristics to something other than a human being. Caporael (1986) suggests that anthropomorphism is so common in modern society that the majority of the time we fail to notice it as anything peculiar. For example, many people have experiences of coaxing and cursing a malfunctioning car, attributing emotions and motives to the mechanical malfunctioning.

individual no longer feels like death is imminent; the spectre of death may continue to impose a shadow over their lives. Indeed, liminality is suggested to carry with it an existential vision, requiring us to confront the fear of dying and the dread of the nothingness that follows death (Little et al. 1998). In spite of improvements in symptoms, the VAD is not a cure, and recipients are still ill. The VAD is keeping these individuals alive moment-by-moment and the threat of deterioration or infection may be seen as a lingering spectre forever in the background of their lives, just as the threat of death is suggested to linger in the lives of those who have experienced cancer (Park, Zlateva and Blank, 2009). Part of learning to live with the VAD is learning to manage the lingering spectre of death in their daily lives.

5.7 Reflections on the VAD

The interviews in this study could be seen as an opportunity for the VAD recipients to reflect back on the experience of receiving a VAD, something that they perhaps had not actively considered in the months or years since the device was implanted. A number of the interviewees described their difficulties processing the series of events that lead to receiving the device. It was not until a period of time had passed following the implantation that they were really able to look back and reflect upon the experience.

It happened so quickly, the decline was so rapid that it wasn't until about 6 month afterward that you actually sit back 'n think my God, did we actually go through all that lot? 'N you think, yeah actually you really are ill, cos things happen so fast and I don't think your brain actually has time to register, it didn't with me, to actually sit back 'n think god this is really serious, cos you're just trying to get on with your day-to-day life. (*Susie, wife of Matt BTT following chronic heart failure, 2 ½ years on VAD support*)

The experience leading up to receiving the VAD was one marked by extreme stress, which some respondents remembered only as a blur, it was not until they looked back retrospectively that the reality of the experience became apparent. The focus for the recipient and their families at the time of VAD implantation is just to get through, living life from moment-to-moment. There is no 'time out' from the experience, unexpected circumstances and contingencies must be managed in real time (Garfinkel, 1967). These individuals are not afforded the opportunity to process the experience whilst it is actually occurring. Upon looking back to their experience of receiving the VAD, respondents expressed gratitude towards the medical team and the VAD itself for offering a second chance at life.

To us it's been a case of you've now got a second chance, 'cos technically you shouldn't have lasted the month, in fact he wouldn't have lasted the month...but for some reason your times not up yet, thank goodness. (*Susie, wife of Matt BTT following chronic heart failure, 2 ½ years on VAD support*)

Susie demonstrates a belief of having a set amount of time to live. This notion of having a 'set time' may reflect a fatalistic attitude to death, suggesting that their death is outside of their control and it is some 'other' whom has the ability to choose when they die.

However, for others thinking retrospectively about the manner in which they were offered the device appeared to cause concern. As discussed in the introduction, under the current UK commissioning guidelines VADs can only be offered as a bridge, to either transplantation or recovery (NHS Commissioning Board, 2013). Some of the respondents had begun to question the temporary nature of the device and the manner in which it had been sold to them, questioning whether it really was intended as a bridge to transplantation.

I know from talking to them that the funding is not available for destination; the funding is only available to BTT [bridge to transplant]. Now the amount they've put, the number [of VADs] they've put in there's no way they're going to get the hearts for them...if it [the VAD] was sold as [a] destination you'd be happy with the fact...the fact that I didn't think it was, whether I'm right or wrong doesn't matter, that's how I thought...it causes me concern if it feels it's going to be longer. (*Simon, BTT following chronic heart failure, 1 ¾ years on VAD support*)

Simon's knowledge about the state of organ donation in the UK and the number of VADs he had seen fitted lead him to question whether the device was really intended as a bridge to transplant. Despite the device not being 'sold' as a destination therapy, he suggests this may have been the intention of the clinicians. It appears he may feel misled to some extent about the potential of receiving a heart transplant, leading to a growing disparity between his expectations regarding the future and the reality of his situation. Having the device 'sold' to him as a temporary 'bridge to transplantation' has elicited the expectation of living with the device in the short term and that in the long term he will receive a transplant. However, over time with the device these hopes and expectations have receded, as he sees more people being fitted with the device, he sees his chances of receiving a heart transplant decreasing.

5.8 Conclusion

The process of receiving a VAD appeared to be complex and potentially fraught with emotion. In order to accept the need for the device the individual must come to terms with their closeness to death and accept the reality that it is their only viable treatment option at that time. However, choosing to have a VAD is not necessarily an easy decision as it involves submitting to major open-heart surgery and accepting a piece of medical technology, a ‘not-self’, into the body.

Furthermore, the actual procedure of receiving a VAD was a majorly stressful event in the individuals’ lives. The stress of this experience could have a lasting psychological impact that could influence how VAD recipients and those closest to them felt about the possibility of further invasive surgery, such as heart transplantation, in the future.

In spite of the distress experienced at the thought of being reliant on a medical device to survive and the risks of the implantation surgery the majority of respondents were grateful to the VAD. The VAD was seen to offer them a second chance at life and extend the time in which they might receive the heart transplant in the future. Concerns were evident amongst some respondents regarding the manner that the device was presented to them. Upon reflection of the implantation period, some respondents questioned the intention of the device as a temporary measure, suggesting it may really have been intended as a more long term solution.

Once discharged from hospital, the recipients (and their caregivers) become responsible for the care of the VAD. For many, particularly those without a history of illness, this marked a big change to their lives. Practices such as personification and anthropomorphising of the device appeared to aid the respondents in coming to terms with the device as something that was intimately and permanently connected to them, this allowed them to begin to see the ‘not-self’ of the device as part of the self. The next chapter addresses how the VAD is practically managed in individuals’ day-to-day lives, and to what extent it comes to be accepted as a feature of their lives.

6

The VAD in Everyday Life

Chapter 6. The VAD in Everyday Life

6.1 Introduction

The previous chapter discussed the experiences of VAD recipients leading up to and immediately following the implantation of the device. Although, VADs are intended as a temporary treatment, a bridge to transplantation, in reality most recipients live with the device for several years. Whilst the VAD can be seen as offering a second chance at life, it also imposes limitations and restrictions. This chapter begins with a discussion of how VAD recipients learn to accept their permanent attachment to the VAD and its external components, the merging of the self and ‘not-self’. This includes the possibility that after a period of time the device may be ‘incorporated’ into their body, becoming part of them, and a discussion of the usefulness of concepts such as cyborg theory in making sense of this. Secondly, this chapter focuses on how the VAD is practically managed in everyday life. How recipients adapt to the physical presence of the VAD, and the care taking it requires, in particular cleaning and dressing the exit wound. Attention is then turned towards recipients’ attitudes regarding self-management, how routines are established, and whether these change or develop over time or in response to bodily signs.

6.2 Activities of daily life

A key part of developing a new normality with the VAD is learning to manage the external peripherals of the device that have become a constant presence in their day-to-day life. Recipients are permanently connected to the VAD, they cannot disconnect it, thus they must learn to adapt to it in all aspects of their lives. This includes the basic task of remembering to pick it up and carry it with you, as well as learning to minimise its intrusion into basic day-to-day activities such as using the bathroom or sleeping.

This constant and inescapable presence of the VAD could be experienced as a source of frustration.

I'm aware that it has to be picked up and taken and carried, I suppose it's like a mum with a baby...you can't just forget it and leave it out of the shop for too long or too often. But you can't leave this [VAD] behind, that's the thing when you think about, does your head in a bit, if that's what you're stuck with. (*Simon, 1 ¾ years on VAD support*)

As Simon states, the constant attachment to the VAD can do ‘your head in a bit’. Similar distress has been observed amongst individuals living with other medical technologies such as diabetics fitted with insulin pumps. When presented with the insulin pump as a treatment

option, diabetics found the thought of being attached to a machine 24 hours a day challenging (Todres, Keen and Kerr, 2010). Simon employs the metaphor of a mother and a baby to illustrate his life with the device. He draws on the responsibility that the device requires which is similar to a mother's for a baby. He is responsible for caring for the VAD, 24 hours a day, seven days a week. Moreover, his responsibility may be even more acute than that of a mother with a baby, he cannot somehow manage to have time off, or a rest from the responsibility, the device is permanently connected.

Like having a baby, receiving a piece of technology, such as the VAD, into the body precipitates a big change to one's life, one that takes time to come to terms with. The VAD makes demands upon the recipients and for many it becomes a central feature of life.

Fred: We have learn to live around the VAD, 'cos it is a life changing thing... your life is never the same again after you've got one

Nancy [wife of Fred]: You adapt around it, don't we?

Fred: You do, yeah. (*Fred, and his wife Nancy, 4 years on VAD support*)

Moreover, for Fred and Nancy at least, receiving a VAD was life changing not just for the recipient but also for the partner. Throughout the interview, Fred and Nancy constructed their experience of living with the VAD using the terms 'I' and 'we' interchangeably. Patently, managing life with a VAD has a massive impact on the partner as well as that of the recipient. Furthermore, this impact may be compounded by the fact that family members are often required to assist the individual in the undertaking of everyday tasks. Similar impacts have been found amongst stroke survivors and their families, with the effects on family members heightened when the patient requires assistance in the performance of everyday tasks (Pound, Gompertz and Ebrahim, 1988).

Learning to manage the device in everyday tasks, such as washing and going to the toilet, appears key in developing a new normality around the VAD. Many respondents described the need for assistance, especially in the initial period following the VAD implantation. Activities that may previously have been performed automatically, and with little thought about what one is practically doing, were brought back into consciousness by the presence of the VAD. Leder (1990) through his concept of the absent body suggested that the natural state of the body is to be outside of our perception; whilst human experience is always embodied the body is seldom a thematic object of our experience rather it is through our bodies that we experience the world. However, the experience of pain may cause the body to 'dys-appear'

and return to consciousness. Like pain, the implantation of a VAD may bring recipients bodies back to consciousness. The VAD, and its physical materiality, are an extension to the individual's body which may be experienced as disruptive, at least until such time as it may be incorporated into the body and become part of the 'form' structure, until the 'not-self' becomes part of the 'self'. During these times of 'dys-appearance' attention may be required for activities which were previously automatic. Amongst VAD recipients, these activities may return to consciousness because it becomes necessary to think about what to practically do with the device. For example, a simple task such as going to the toilet may become fragmented with each constituent part made present (Irving, 2005); the individual has to think about what to do with the external components of the VAD at every step in the process.

Even going to the toilet...you've got a big handbag across you and where do you put it, you know? And little things like that, you have to make adjustments. (*Fran, 4 years on VAD support*)

Fran's use of 'even going to the toilet' emphasises just how far reaching the impacts of the VAD are on her life, even extending to such basic everyday tasks. Similar accounts have been found amongst those living on long term oxygen support who must think and plan for any activities in which they engage, be they physical, psychological or social (Ring and Danielson, 1997). It is not the VAD recipients health per se that restricts their activities, but rather the physical presence of the device and the need to protect it (and hence them) from damage.

The physical presence of the VAD is an extension of the recipient's body, which both constrains and enables everyday practice. Those living with VADs have to learn how to adapt the device into the choreography of their everyday life. Due to the device's material structure, with its external driveline, recipients must consider it when moving in and through the house.

When I'm in short spaces...little knobs on doors, draws...getting them caught on that [driveline]...you laugh at it...and you unlatch yourself, and it's doesn't hurt, but it's just like for a slight second you go 'Ohh sugar, one of these days it's [driveline] gonna snap'. (*Ben, 2 years on VAD support*)

Ben's quote demonstrates that the VAD can be disruptive to even the most basic of behaviours. Furthermore, it is not only the behaviour that is being disrupted but also how places and objects are viewed. The home, previously viewed as a place of safety, becomes full of unanticipated threats such as doorknobs that may pull the driveline and damage the exit wound. The physicality of the VAD leads previously innocuous objects to be seen as potential

dangers. The body-in-the-world ceases to be taken for granted during times of illness, requiring the re-learning and re-inhabitation of familiar places through re-alignment of the senses (Irving, 2005). During the mid-1990s researchers at the Massachusetts Institute of Technology, calling themselves cyborgs, carried computers and radio transmitters on their backs, they had to learn to walk as a new creature, learning to re-inhabit their changed bodies (Turkle, 2008). Similarly, the external components of the VAD may disrupt and extend the natural boundaries of the body, requiring the recipient to re-learn how to inhabit both their own body and their physical environment.

Over time it is possible for the VAD to fade from consciousness, however incidents such as getting the device caught, as described by Ben above, can cause it to re-enter consciousness, being-at-hand. These times when the VAD reveals itself to consciousness were often viewed with frustration and irritation.

April: I think a lot of it is your attitude as well. The VAD is a fantastic machine.

David [April's husband]: Sometimes you call it worse than muck.

April: Ohh, I mean sometimes, I've got a tendency to put it down on the bed (David: and forget about it) and I'll get dressed, and even three years down the line, I'll still go to walk away and you'll feel it tug and you'll think 'this flaming thing'. Or you turn over in bed and it's there, and you know you just want to throw it away. (*April, and her husband David, 3 years on VAD support*)

April indicates that incidents of the VAD intruding into consciousness could still occur even after several years of living with the device. These occurrences were a stark reminder of the otherness of the device. Technologies, like the VAD, have a dual identity, similar to the body in Cartesian thought, where the corporeal body is believed to be entirely separate from the mind. Whilst they can be seen as an extension of ourselves, subject to our will, they are also alien, 'not-self', invasive forms of non-being that subjugate us, undermining our very notion of who and what we are (Jackson, 2002).

The most evident impact on recipients' everyday lives appears to derive from the external components of the device, which the individual is required to carry, care for, and protect from potential harm. This appeared to be a source of frustration, as a functioning body is usually absent from consciousness in the undertaking of day-to-day tasks. However, over time spent

living with the VAD many recipients developed approaches to reduce the intrusion of the device, aiding them in the undertaking of everyday activities.

6.3 Affordances and adaptations

The physical nature of the VAD obviously affected recipients' day-to-day lives, requiring the recipient to learn how to re-inhabit their changed bodies. Many respondents described how they actively worked to adapt the materiality of the VAD into their lives, in order to try to reduce the impact on their daily functioning and allow basic tasks to recede from consciousness once more. These adaptations could be as simple as having something next to the toilet to rest the VAD bag on:

Going to the toilet, you have a little bin at the side of the toilet so you can rest it on there. (*Matt, 2½ years on VAD support*)

Utilising other objects, as Matt describes here, could ease undertaking of such basic activities. Placing the bin next to the toilet provides a solution to the problem of what to do with the device, potentially enabling the VAD to retreat from being unready-to-hand¹¹, further we might suggest that the VAD is obstinate because it is a hindrance in the pursuit of using the bathroom.

Bathing was one aspect of day-to-day life in which respondents appeared particularly keen to adapt the device to best fit into their lives. Upon receiving the VAD, the clinical team provide specific guidance around washing and bathing, this includes the prohibition of baths. This guidance is intended to reduce the chances of the device becoming damaged or the exit wound becoming wet, increasing the chances of infection. However, many respondents did not passively accept this guidance, but instead sought ways that would allow them to engage in pleasurable and valued activities such as bathing without endangering the device.

You're not supposed to have a bath, you know that...but I do. Only because Matt and them, the very naughty ones, told me they got a bath...so much water so it doesn't go up onto here [the exit wound], and he said just to lie down in it...I can put this [VAD] in the shower bag and then I can hang that on there [towel rail], and then I can get in the bath, and it doesn't get wet at all. Because it's always out of the water. (*Simon, 1 ¾ years on VAD support*)

¹¹ Heidegger (1962) suggests that there are three manners of unreadiness to hand: conspicuous, obtrusive, and obstinate.

VAD accessories, such as the waterproof shower bag provided by the manufacturers, were utilised in order to enable Simon, and other respondents, to have baths whilst minimising the chances of damage or danger. Simon indicates that he only started engaging in this behaviour following conversations with other VAD recipients. He changed the manner in which he orientated to and dealt with the device in response to advice from other recipients. Simon and the other 'very naughty ones', as he describes them, have subverted the use of the waterproof bag, designed for showering, in order to enable them to have a bath.

It is suggested that technological artefacts are socially shaped (Hutchby, 2001; Schraube, 2009), and that it is common for technologies to be given alternative uses or subverted to fit the needs of the individual (Bijker and Law, 1992). Furthermore, Grint and Woolgar (1997) suggests that technologies should be treated as texts that are written in certain ways by their developers to be read by the user or consumer. The motivations of these writers and readers can differ. Whilst the writers may seek to impose certain meanings upon the artefact to constrain the interpretations of the user, the users may seek readings best suited to the purposes they have in mind for the artefacts. The respondents demonstrated this, despite the manufacturers intended meaning for the length of the driveline and shower bag, these are subverted in order to facilitate other activities. The externals of the VAD are not designed to be waterproof; they do not afford patients the possibility of a bath. The manufacturers' of the VAD have a theory of the user which does not involve the behaviour of having baths, and it appears that they believe users will accept this theory of use and the limitations that it carries.

As discussed above, recipients' orientation towards the VAD may be influenced by social factors. Contact with others and social motivations may alter how the device is viewed. Actor network theory suggests there is a mutual constitution between society and technology (Prout, 1996); there is a reciprocal relationship between the two. Devices are always subject to processes of translation when humans interact with them, and each configure and reconfigure the other in unpredictable ways. This process of interaction can be observed amongst VAD recipients in the manner in which they both adapt the VAD to fit their lives and adapt their lives to fit around the VAD. Such a process can be observed in recipients' bathing behaviours. Whilst the physical composition of the device limits the behaviours in which the individual can participate, the recipient also works to minimise this impact by changing the manner in which they engage with the device.

Another explanation of recipients' orientation to the VAD technology is the notion of 'affordances'. Technologies can be read and constrained by the affordances they possess (Hutchby, 2001). The term 'affordances' was developed by Gibson (1977); he suggested that

when we look upon an object we perceive its ‘affordances’ rather than its qualities, what we see is what the object will allow us to do or achieve. The affordances viewed in an object or a technology are dependent upon the perceiver; however, they are not freely variable. For example, a telephone will always offer certain affordances that a toaster does not possess, one offers the affordance of connecting socially with another person, and the other does not. While the affordance of the driveline in facilitating bathing was not immediately perceivable to Simon, it became visible after discussion with others living with VADs. The manner in which recipients orientate to these affordances is interesting. In Simon’s account of using the length of the driveline to allow him to have bath he constructs this behaviour as something he is ‘not supposed’ to do, and those who enlightened him to the possibility as the ‘very, naughty ones’. Others referred to this bathing as ‘cheating’:

Just daft things like a bath, you couldn’t even had a bath, well you can cheat, you can just put about three inches of water in the bath, but that’s not really a bath, so as long as you hold this out of the water...you don’t realise the things you miss until it’s not here, just having a decent you know soak in the bath it would be fantastic, but just daft little things. (*Stephan, 11 months on VAD support*)

References to ‘cheating’ have also been found amongst those living with a number of chronic conditions, including diabetes, HIV/AIDs, and multiple sclerosis (Thorne, Paterson and Russell, 2003). Whilst these individuals were committed to maintaining a healthy lifestyle, they all reported ignoring or violating it upon occasion in order to make room for a valued identity. These violations were articulated as an essential aspect of living a meaningful life (ibid.). However, we could also interpret Stephan’s use of the word cheat in another manner, it is not a ‘proper bath’ that is afforded to him by the VAD, which is evident as he says ‘that’s not really a bath’. Matt reinforces the latter interpretation of cheating:

I can’t have a bath, well I can, and I do, but you can’t have a proper bath, you know a deep, hot water, relaxing bath. (*Matt, 2 ½ years on VAD support*)

The language employed by Matt in the quote above creates an image of a ‘real bath’, which is a ‘deep, hot water, relaxing’ bath. This is the bath desired by the respondents in this study. Matt’s imagery indicates that this is something that he has thought about before, perhaps even longs for. The ‘awkward’ shallow bath, where you need someone or something to hold onto the device, does not fulfil this longing. The type of baths that respondents were able to

achieve was a compromise; it allowed them some semblance of this valued activity without significantly endangering the device. The materiality of the device affords the recipients these compromises.

Such compromises may be an example of ‘trading off’. ‘Trading off’ is a behaviour which has been identified in those with post-polio respiratory disease (Locker and Kaufert, 1988). Often those living with medical technologies experience losses as well as important gains, and managing day-to-day life requires a balancing these of benefits and losses. ‘Trading off’ involves maximising the advantages offered by the technology and minimising the disadvantages by reorganising daily living and psychological orientation (ibid.). That the interlocutors manage the device in order to allow them to engage in valued activities has positive implications for those living with VADs. It indicates that recipients are active in adapting to living with the device; developing compromises and workarounds to try and best fit the device into their lives and allow them to engage in activities that they enjoy. However, such active adaptation may lead to the adoption of less than optimal routines, as has been observed amongst those living with other medical technologies (Lehoux, 2004). Such behaviour was evident amongst the respondents:

Nancy [wife of VAD patient]: I think we probably get sort of blasé to certain things, you sort of get in autopilot...

Fred: We’ve got to the stage now where we have to sort of say to each other ‘VAD bag?’ ‘Yeah’, ‘VAD bag two batteries?’ ‘Yeah, ok’

Nancy: It’s becoming so familiar that we’ve sort of become caught out a couple of times, we’ve actually forgotten things. (*Fred, and his wife Nancy, 3 years on VAD support*)

Fred, his wife and Nancy, had been living with the device for many years and it appeared that they had begun to take for granted the work required to care for the device. Maintaining optimal routines in regards to caring for the device is of the utmost importance for VAD recipients, laxity in these behaviours may result in potential risks to their health and safety. In addition to the actual VAD device itself, there is an array of associated accessories and equipment that recipients must remember to carry at all times. These accessories include spare batteries and Hollister clips. Many respondents had a bag, in addition to the VAD bag, which housed all these associated components. Comparisons can be drawn to the experience of diabetics living with insulin pumps, whose need to always be prepared in case of a technical failure requires them to carry additional accessories on their person (Saarinen et al. 2014). For

diabetic patients the demands of the technology can cause the insulin pump to be experienced as both a shackle and a lifeline (Garmo, Hörnsten and Leksell, 2013). Similarly the VAD, whilst essentially performing the role of a life support machine for recipients, imposes certain limitations which may also lead it to be viewed as a shackle and frustration.

Respondents appeared to actively seek ways to reduce the intrusion of the device into their lives. This has positive implications, suggesting that it is possible for VAD recipients to live in harmony with the device, that adaptations can be found which allow individuals to once again move seamlessly through their lives. However, these adaptations and their normalising effect on the device could result in the care regimen being taken for granted.

6.4 Care taking of the VAD

The VAD, like many medical technologies, requires the individual to play a role in its management. The relationship between the individual and the VAD can be seen as interactive; the VAD does something to the recipient whilst also demanding things of them. Diligent care taking of the VAD is essential for the device to be an effective treatment option. Compliance with medical regimens has been suggested as an everyday reality for patients who are living with a chronic illness (Atkins and Ahmad, 2000). The impact that these medical regimens have on patients' lives has been noted.

Medicine gives the chronically ill reason to hope, even as it produces limitations with which these persons have to live by making adjustments to meet every day requirements. Pierret (2003: 14)

VADs confer expectations to the recipient in terms of care taking. As well as the basic tasks of managing the physicality of the device, of remembering to pick up the VAD and take it with them, recipients are also required to change batteries, controllers, manage medications and clean and dress the exit wound. Similarly to those self-administering dialysis (Ådahl, 2013), a specialised knowledge of the body and the VAD technology is essential to do 'Being' a VAD recipient.

Of these care taking responsibilities cleaning and dressing the exit wound is ultimately the most important. The exit wound, located in the lower half the individual's abdomen, it is the point where the driveline exits the individual's body. VAD recipients must also be diligent when washing, ensuring the wound does not get wet as this may increase the risk of infection. The exit wound is covered by a dressing that has to be changed several times a week. Infection in the driveline is a devastating outcome, one that can potentially lead to death.

Recipients and/or their carers are responsible for cleaning and dressing the wound on a day-to-day basis, they are taught the technique prior to discharge.

When I went home, I could never do it myself, I used to get someone else... I think it's a lot better to do it yourself, because if someone else is doing it they're only doing it to their cleanliness... if you're doing it yourself you can go 'ahh I've gotta get right in there', you'll know when it hurts... and someone else doesn't, they pull it and think 'ahh shut up, it cannot hurt that much', but it does. When you do it yourself you don't get no pain, you know exactly how clean you're getting it and you've only got yourself to blame if something goes wrong... I just feel like you've got a lot more responsibility. (*Ben, 2 years on VAD support*)

Some, like Ben, preferred to take responsibility for cleaning the driveline themselves, accepting that they would be to blame if an infection were to occur. Over time with the VAD, Ben's attitude towards the driveline appeared to change; he was initially avoidant of this task delegating the duty to his father. Concerns about cleanliness appeared to be key in this change, believing that others would not be as thorough as he would. Furthermore, cleaning the wound himself affords him greater control in avoiding other unpleasant occurrences such as pain that may be experienced during the cleaning process. Grant echoed this attitude:

For the first couple of weeks I had district nurse come out and do it, but I realised straight away that I could probably do a better job than them and from that point on I just looked after it on my own. (*Grant, 2 ½ years on VAD support*)

A preference for taking responsibility over caring for the exit wound appeared particularly prevalent amongst the younger interviewees, such as Grant and Ben. These interviewees may perceive that they are able to do a better job because they know their own bodies best, so they are in the best position to anticipate, identify, and respond to any changes. However, not all respondents shared this view; many delegated the duties to their partners.

She's [wife] behind me all the way, she's the one who changes me dressings... she's been better at it than the couple of times [the nurses did it]... the second time I came in here they took a swab off me chest where this lot had just started to knit back together and they sort of caused an infection in it, and she was very upset about that because she's been doing my driveline without any problems and then they cause this, she was saying

they shouldn't have been doing that...what did they do to cause this?

(Russell, 2 ½ years on VAD support)

Although Russell delegated the responsibility of cleaning and dressing the exit wound to his wife, he echoes the sentiments of Ben and Grant, his wife is more adept at cleaning the exit wound than the nurses. Respondents expressed confidence in their caretaking, believing that either they or their carers had developed expertise in caring for the wound, possibly greater than the skill of the health care professionals. This expertise was evidenced by their successes in avoiding infection.

The interlocutors differed in the practical routine they adopted for cleaning the exit wound, some chose to stick to the routine taught to them prior to discharge, whilst others tweaked it to best suit them.

My wife's been a big help there doing the dressing, that's her job, she got taught how to do it then she's tweaked it to her way, and my biggest enemy is infection, so with the driveline site...she always has a good look over it.

(Gary, 2 years on VAD support)

Gary, and his wife, recognised that infection was the biggest threat to his life and as such, the task of cleaning and dressing the exit wound was not one to be taken lightly. Gary's wife had 'tweaked' the routine to suit her and Gary's needs. Other respondents indicated that this 'tweaking' was a trial and error process, it evolved over time through the testing of different techniques and products.

Lyn [Ian's wife]: We've changed the dressings...the actual type of dressing, how many different types of dressing have we had on it? We've had a bigger one, and we've cut the bigger one and now we have a butterfly dressing, so the lines secure...

Ian: It holds the driveline much better. *(Ian, and his wife Lyn, 7 months on VAD support)*

Over the six months that Ian had been living with the VAD he, and his wife Lyn, had tried out many different types of dressing before finding the one that best suited their needs. Evidently, people have different needs and requirements, thus a 'one size fits all' approach to wound care and dressing may not be appropriate. Adapting the routine to fit individual needs may allow those living with VADs to take ownership over the behaviour and the device.

Routines for cleaning the exit wound can also be adapted according to activities that respondents are planning to engage in:

I keep me self busy...I'll help me friend if they're putting up like a wardrobe, I'll cut the timber...instead of doing me dressings like four times a week, I've gotta do me dressings that day, before I do it, and then I've gotta do it again when I get home, just in case any dusts got in it. (*Ben, 2 years on VAD support*)

Ben changed/increased his wound cleaning regimen if he was planning to engage in behaviours that might increase his risk of infection. Rather than avoid what he identifies as potentially dangerous behaviours, he adapted his care regimen to minimise the risk of negative occurrences. Ben appeared to understand the importance of caring for the wound; it is something that needs to be done to ensure his own well-being. Again, this indicates that recipients are active in how they adapt to living with the device. By taking control over the care regimen, they are able to engage in valued activities rather than passively accepting the potential limitations of the VAD.

Adaptions to wound care were also made in response to bodily signs and signals.

While it [exit wound] was really gungey, it was leaking out...and we were having to change it twice a day, so it was changing it 9 o'clock in the morning and changing it sort of 9 o'clock at night. (*Nancy, wife of Fred, 3 years on VAD support*)

Nancy describes how as she, and her husband, responded to bodily signs such as puss and liquid around the wound by increasing the frequency with which they changed the dressing. The frequency was increased in order to ward off potential infection. Fear of developing an infection was a major motivator for good wound hygiene.

Lyn [wife of Ian]: It probably wouldn't need changing every other day, I like to keep it...

Ian: The Flaminal starts to get crusty after two days...it gets crusty and I think if you left that too long the crust would build up too much...so I like to have it changed every other day...just to make sure no infection. (*Ian, and his wife Lyn, 7 months on VAD support*)

For the couple above, the fear of developing an infection leads them to increase the frequency with which they changed the dressing. For Lyn and Ian the crust that builds up on the exit

wound is seen as a potential risk factor for infection. Adjusting their routine to deal with these bodily signs reduced their anxiety about an infection occurring, giving Ian the confidence that he had done everything in his power to protect himself. Such responses to bodily signs may be seen as an example of 'body listening' (Thorne, Paterson and Russell, 2003). Over time living with the VAD and dealing with the exit wound they may develop a sense of what is a normal for their wound; this may include the appearance, smell or even feel of the wound. This knowledge allows them to adapt their behaviour accordingly. These adaptations and ability to anticipate problems indicate that patients had reached a level of competence and acceptance in living with the VAD. Furthermore, this approach appeared to be useful in taking control of their condition.

6.5 Technology and identity

Developing a new normality with the VAD involved more than the practical adaptations to the materiality of the device. Chapter 5 discussed VAD recipients' initial reactions to the VAD technology and the thought of it being implanted in their body. Developing a life around the VAD involved making sense of the VAD technology and what it meant for their body and identity. Technology is playing an increasingly important role within health care, broadening treatment options and saving the lives of those who are critically ill. Whilst such technologies can be hugely beneficial, they can also prove challenging. Recipients may experience difficulties accepting the technology into their bodies in what is often a very intimate manner (Jackson, 2002). Such difficulties may be particularly acute amongst those with heart technologies such as VADs, as the heart is arguably the most intimate and emotionally charged aspect of the body.

The role of the VAD in the treatment of advanced heart failure is to support, or take over, the heart's role of pumping blood around the body. The VADs currently used by the implanting centre from which the participants in this study were recruited were 3rd generation devices, which rather than pumping blood around the body in a similar manner to the heart, circulate blood in a continuous stream. Side effects of this generation of device include a weakening or loss of pulse, depending on the extent to which the device is responsible for pumping blood. These bodily functions that are disrupted and changed by the device, the pulse and heartbeat, are normally seen as signs of life. Furthermore, they are bodily functions with a high degree of symbolism and meaning attached to them. VAD recipients must accept a piece of technology that not only alters the body's appearance, but also the manner in which it functions. Such changes may have the potential to alter the manner in which the individual

perceives themselves, and their body. Following the VAD implantation, the respondents could be suggested to have become posthuman in some way.

He [son] liked the idea that I didn't have a pulse anymore, for example he hold me that I was half man, half zombie. (*James, 11 months on VAD support*)

For James' son, the idea of looking upon his father as a zombie may have been a useful tool in dealing with his father's illness and making sense of the 'otherness' of this piece of technology that was permanently attached to him, allowing him to conceptualise his father's illness as something exciting rather than frightening. Similar conceptualisations were evident within Fran's family.

The kids call me bionic woman, 'cos I've still got the pacemaker and the VAD and the bits of metal that keeps your chest back together, it's a bit weird. (*Fran, 3 ½ years on VAD support*)

Here, Fran calls upon the weirdness or unnaturalness of having various pieces of technology implanted in her body. The terms 'zombie' and 'bionic woman' evoke images from science fiction. Receiving technologies into the body, such as VADs, may give rise to questions about the self and the body. Such questions may be enhanced by the fact that the technology takes over an essential bodily function. Amongst patients on dialysis, the visibility of the blood as it passes through the machine is seen as a concrete display of how the machine is substituting the human body (Ådahl, 2013). Similarly, the perceivable changes to the heart's functioning following VAD implantation may draw attention to the fact that this vital organ is being substituted by a machine. Several theories have been developed to make sense of the manner in which technologies can change the human body. One example is posthuman theory which suggests that there are no essential differences between biological or cybernetic organisms. According to this viewpoint the body is the original prosthesis which we learn to manipulate, and the use of extensions or replacement of body parts is merely a continuation of a process which began before we were born (Hayles, 1999). According to this theory the VAD should be conceptualised as no different to any 'natural' component of the body, it is merely one aspect of this continual process of extension and replacement.

Another approach for conceptualising the impact of the VAD on an individual, their body and sense of self, is cyborg theory. A cyborg is a scientific chimera, which comes into existence when two types of boundaries are simultaneously breached, such as human and machine (Williams, 2003). Mazis (2008) suggests that what makes us cyborgs is the way in which we

are put into question by machines, and have been transformed in who we are by our co-joint being. Chorost (2005) wrote an in-depth account of his experience of becoming a cyborg after receiving a cochlear implant. He suggested that the thought that the 'weirdness' of attaching a data terminal to his head would someday become a part of his day-to-day life was one of the most frightening aspects of his journey, as the normality and mundanity of this activity would signify that he had truly changed. Indicating that it is possible for an individual to accept a technology into one's life. Indeed, the respondents of this study recounted how they became accustomed to the VAD and its presence. For some this went as far as accepting the device as part of their body.

When I'd had it about three month it more or less become, I know it's part of me, but it actually became part of me. I'll get up now and just pick it up automatically, I won't think about picking it up and I can change the batteries in the middle of the night, in the dark and stuff like that. (*Matt, 2 ½ years on VAD support*)

A temporality to Matt's account is evident. There is a clear distinction between when he knew the device was part of him, in that it was located in and attached to the body, and to it becoming a part of him as an extension to the self. The issue of whether or not a medical device is part of the body has been hotly contested. Analogies have been made to property laws distinguishing between fixtures and fittings, with medical implants deemed to be biofixtures, whose ascribable status, whether part of the body or not, lies with the individual (Paola and Walker, 2000). Technologies have been suggested to be progressing faster than our philosophical ability to process them and what they mean for us as humans (England, England and Coggon, 2007). The new category of 'integral devices' is suggested for medical devices implanted into the body. These integral devices require new rules as they fall somewhere between a form of treatment and a part of the body (ibid.). Studies employing cyborg theory have been criticised for their tendency to silence the voices of those who are actually living as cyborgs (Oudshoorn, 2015). It is suggested that the individual is actively involved in sustaining their hybrid body, and that lifelong monitoring is required in order to maintain this fusion of humans and technologies (ibid.). Whilst Oudshoorn (2015) developed her concept in reference to ICDs, I suggest that this effect is more acute in the case of persons with VADs, where the demands that the device imparts may prevent it from receding from the recipients' consciousness.

Receiving a piece of technology into the body in as intimate a manner as the VAD requires work on the part of the recipient to make sense of this merging of the self and 'not-self.'

Although, both posthuman and cyborg theories offer a potential means for conceptualising the experience of VAD recipients, they are somewhat limited in their ability to explain what it means to 'Be' a VAD recipient. Neither of these theories help us understand how recipients practically manage their new lives with this technology and how this fusion with technology is maintained.

6.6 Conclusion

Accepting the VAD into their lives and bodies appeared to take work on the part of the respondents in this study. This work included learning to manage the VAD in everyday life in order to minimise the disruptiveness of its impact. The materiality of the VAD, with its external components, could cause disruption in the undertaking of daily activities. The theory of affordances offers us a means of understanding the manner in which recipients manipulate the physical materiality of the device to facilitate the undertaking of simple everyday tasks. Such 'work arounds' appeared to be successful in enabling recipients to live successfully with the device, allowing daily activities to once again recede from consciousness.

The demands of the VAD on individuals, specifically the care taking required, are an important aspect of 'Being' a VAD recipient. Furthermore, such demands may limit the extent to which it is possible for the device to be embodied, as they act as a constant reminder that there is something 'other' attached to the self which acting as a prosthetic organ.

Having a piece of technology inside and attached to one's body in the manner of the VAD understandably provokes questions about what this means for the individual's identity, it is a merging of the self and 'not self'. It appeared that over time it was possible, for some respondents at least, to incorporate the device into their sense of body and self. Cyborg and posthuman theories offer ways of understanding these changes to the recipients' identity. However, these theories fail to provide us with a real understanding of what it means to 'Be' a VAD recipient managing this technology in everyday life. This thesis, and in particular this chapter, is aimed at demonstrating the work that is required in order to establish and maintain this hybrid body, and that a failure to engage in this work leads not only to a threat to the hybrid body but also the health and life of the individual.

This chapter focused on the manner in which the VAD impacts practically on recipients everyday lives. The next chapter will discuss the role in recipients' identities and its potential to cause stigmatisation.

7

Impact of the VAD on Identity and Experiences of Stigma

Chapter 7. Impact of the VAD on Identity and Experiences of Stigma

7.1 Introduction

The previous chapters of the thesis have focused on the VAD recipients' attempts to learn to live with the device and fit it into their lives. Chapter 6 dealt with the impact that the external components of the VAD could have on the practical undertaking of day-to-day life. It was evident that work was required on the part of the recipient to become accustomed to the presence of the VAD in their lives. Nevertheless, such work can afford the integration of the device into everyday life. In addition to these practical considerations, the VAD also appears to have relational impacts; these are discussed in this section of the thesis. This chapter begins with a discussion of the impact of the VAD, and its external components, on the recipients' sense of identity. It is suggested that the visibility of the device may lead to changes in the way recipients are orientated to. The chapter proceeds to discuss the role of the VAD as a potentially stigmatising object, outlining the methods employed by VAD recipients to control the visibility of the device and in turn how others orientate towards them. Particularly important in managing this stigma appeared to be the practice of disguising the device when out in public; this behaviour is discussed in reference to the sociological concepts of passing and covering. Finally, the chapter discusses how the VAD and its external components may interact with the practice of traditional forms of masculinity.

7.2 Becoming 'other'

The preceding chapters discussed the VAD as an object, as something other or 'not-self'; this section will discuss the potential of the VAD to change the identity of the recipient and their process of becoming 'other'. As VADs are a relatively recent development in the treatment of heart failure many health care professionals outside of specialist centres have limited knowledge or experience of these devices. Furthermore, the VAD itself is unique, comprising of components both inside and outside of the recipient's body. Interviewees' accounts suggested that encounters with health care professionals unfamiliar with the device generally resulted in two outcomes. Firstly, the device was often looked upon as an object of fear that the health care professional was unsure how to manage.

I think when the paramedics first arrived...when they walked in through the door and saw Paul, 'cos he just had his computer [VAD], they just stood there and looked, didn't they? And they apologized later, 'cos he said 'we're so sorry', but they said 'it's a LVAD, we had no idea what to expect'...but I've got a card that I have to give to any medical, paramedics or anyone that comes...they did want me to travel in the ambulance with them, 'cos

obviously they don't know how to change batteries, computers. Paul wouldn't have been well enough to do it himself, but I mean that was no problem... But they do state that if he is poorly, 'cos I know more than any of them [paramedics], it's best if I stay with him so that people know what to do, and aren't sort of scared of dealing with it. (*Hannah, wife of Paul, 4 months on VAD support*)

Hannah's account suggests that she believes the receipt of the VAD changed the way that others orientated to both her and her husband. The device led to the development of a new identity for her, as Paul's carer, and an expert in dealing with the VAD. The paramedics' reactions indicated that whilst they may have heard of the device, they possessed limited knowledge about how to practically deal with it, preferring to defer to Hannah. Others provided more extreme accounts of health care providers refusing to engage with the device.

Ian: Nurses didn't know how, nurses could change a battery that was it, didn't have a clue how to change the controller

Lyn: Didn't want to know. 'Cos I went in and I said 'look here's Ian's controller, spare controller and the dongle', 'we don't, we don't need to know that' I said 'well, what happens if his controller goes off?', 'He'll change it himself'. I says 'Ian'll not be able, might not be conscious'

Ian: I mightn't even be conscious.

Lyn: They just didn't

Ian: You know they weren't interested... That's why I don't want to be involved with them anymore. (*Ian, and his wife Lyn, 7 months on VAD support*)

Ian, and Lyn, found their experiences with staff at non-specialist hospitals to be disappointing and frustrating. The VAD plays a vital role in Ian's life and treatment, and distress at those supposedly responsible for one's care refusing to engage with the device is understandable. These negative experiences had left them reticent to be involved with the hospital again, choosing to go elsewhere whenever possible. It appears that the presence of the VAD may change the manner in which recipients are perceived and orientated towards by health care professionals. To those unfamiliar with the device the individual is no longer just a heart failure patient but has become a heart failure patient with a strange appendage attached, which they are unsure how to manage. The individual has become something 'other', this may also

present a threat to the natural order of the clinician-patient relationship, leading the clinician to feel that his position is threatened because he has to defer to the patient themselves or their carer.

Alternatively, having the VAD could also result in the recipient being used as a 'teaching moment'. Many of my interlocutors recounted experiences of being in hospital and having trainee and junior staff gathered around their bed to learn about them.

Terry [Jan's husband]: When we've gone into A & E, quite a few times they've set up the student nurse, or someone like that, where they'll send them knowing that she [Jan] hasn't got a blood pressure or a (Jan: pulse) pulse, they'll send the nurse over to do it...they've gone back for different machines 'there's something wrong with this one'

Jan: Yeah, but we're tipped off by the head, by the sister, because these people, these nurses, need to learn.

Terry: The thing is as well, especially the pulse one, they'll go 'you get a pulse' and we'll wait for them to say 'yeah, yeah it's fine, yeah, yeah', and then they can go 'No, not really because she hasn't got one, so you haven't got a pulse at all.' So a bit cruel but they find out a little bit more (Jan: they need to learn) about the person. (*Jan, and her husband Terry, 4 years on VAD support*)

Whilst many enjoyed participating in this teaching, being singled out in this manner is likely to compound the individual's sense of being different or 'other'. This further supports the notion that the VAD changes the identity of the recipient from heart failure patient to something 'other.'

7.3 Sensory presence of the VAD

Beyond interactions with health care professionals, the VAD also appears to carry a relational impact on recipients' day-to-day interactions. The external components of the device render it visible to both the recipient and others. During the interviews, it was evident that the presence of these external peripherals had an impact on the recipients and those closest to them. The visibility of these components could be seen as a signal of the individual's illness, bringing an awareness of it back into consciousness.

Yeah, I can forget but then I think you're always reminded because you can see the [VAD] bag. And when you can hear it whirring...so yeah visually

you can forget when you can't see the item, but it is always in the back of my mind. (*Hannah, wife of Paul, 4 months on VAD support*)

For Hannah, the visual presence of the VAD acts as a constant reminder of her husband's illness. Whilst Paul's condition was greatly improved following the VAD implantation, the constant presence and visibility of the VAD keeps his illness in her consciousness, preventing it from becoming transparent. Thus, for the VAD recipient, and those closest to them, the visibility of the device may act as an unwelcome reminder of their illness and vulnerability, the 'not-self' is a reminder that they are 'not themselves'. Hannah also indicates that the device holds an audible presence; this was also a feature of other's accounts. However, accounts of the auditory intrusions of the VAD indicated that these are on a different level to the visibility of the device.

Sometimes when you get reflective, like having a bath, you go 'am I always going to hear this?' So yeah, you're aware of it at the times when you don't want to be aware of it, when you're relaxing in the bath and when you're trying to go to sleep, the rest, I don't notice it now. (*Simon, 1 ¾ years on VAD support*)

Unlike the visual presence, these auditory intrusions were not constant, but rather sporadic, usually occurring at times of quiet relaxation. As such they may carry the potential to be experienced as more disturbing as they occur when least desired. For Simon, these intrusions provoked thoughts about his future, would a time come when he no longer had to face such intrusions? Would there be a time when he no longer had the device? Such thoughts highlight the liminality of his situation; he has no way of knowing what his future may hold. The VAD, through its visual and auditory presence, intrudes into the consciousness of the recipient and those closest to them, making transparent the vulnerability of the individual and bringing thoughts about the future into their horizons of awareness. The sensory presence of the device renders it, and the illness present, to the recipient and those closest to them.

The presence of the VAD, particularly visually, also has the potential to influence the recipients' social position. As VADs are relatively unknown amongst the general population, the visibility of the device could be seen as an indicator to others that they are in some way 'not normal'. For Ben, the visibility of the device was a cause for concern; he worried that it might prevent him from resuming his position within his friendship group.

Obviously if you get telled, you're gonna have all this on and you're only young you're gonna panic and think 'ahh, what's me pals going to think?'

Am I still going to be one of the boys sort of thing? Cracking on with the lads and that? But it doesn't change anything. (*Ben, 2 years on VAD support*)

Ben recounts how he was concerned that the visibility of the device might lead his friends to treat him differently. Ben was the youngest participant interviewed, having received the VAD whilst still in early adulthood. Such concerns are understandable, especially in someone of his age, who had not only been seriously ill and in hospital, but was now constantly and visibly connected to this technology, highlighting his difference from his friends. Changes to one's social standing may often follow the development of a stigmatising attribute. The stigmatised individual is suggested to hold a special place in society (Goffman, 1963):

He [sic] is a member of the wider group, which means he [sic] is a normal human being, but that he is also different in some degree, and that it would be foolish to deny this difference (149)

Following his illness, Ben is indeed different from the rest of his social group, and the presence of the VAD prevents any denial of this. The chronically ill person has a dual identity; they are at one and the same time both inside and outside the group (Exley and Letherby, 2001). Ben appeared concerned about the impact of the device on his social standing, that he might be relegated to the position of a 'stranger'. For Simmel (1971) the word stranger¹² refers not just to the newcomer, but also to one who having come from some other place assumes or is assigned a particular position in the social structure. Fortunately, for Ben, his fears of becoming an outsider or stranger appear to have been unfounded and have since been alleviated by his friends' positive reactions to the device.

The visual presence of the VAD appeared to impact on the VAD recipients, their significant others and family members. However, the actual impact of the device differed between these groups; it could be perceived as a reminder of the illness or an indicator of one's 'outsider' status. The visual presence of the device and its potential impact on social standing was a cause for concern, particularly amongst younger interviewees.

¹² McLemore (1970) has criticised how the concept of the stranger is often applied suggesting that there is a tendency to turn immediately to Simmel's (1971) concept when the traditions of other authors such as Wood (1934) and Schütz (1944) may be more appropriate. McLemore (1970) differentiates between the stranger as a 'marginal man' or as a 'newcomer'. In the instance of these VAD recipients, Simmel's (1971) concept of the stranger seems to be most appropriate because they are not a newcomer but are assigned a position outside of the social structure.

7.4 The VAD as a stigmatising object

In addition to the impact on relationships with friends and loved ones, the impact of the visibility of the VAD also appeared to extend to the wider population. Respondents expressed concerns that the VAD may mark them out as being ‘different’ or ‘not normal’, one way of understanding this is that the visibility of the external components of the device may leave VAD recipients vulnerable to experiencing stigmatisation from others. Stigma¹³ is a social process whereby adverse social judgements result in the experience or anticipation of negative consequences; this may include blame, exclusion, devaluation, or rejection. This negative social judgement relates to some enduring feature of an individual. The process of stigmatisation can be viewed as a means of maintaining social order, as honourable and upright behaviour can only be maintained if the breach of norms is a realistic and publicly marked possibility (Wittgenstein, 1953).

Stigma is a concept which is frequently employed in social science, however concerns have been raised about the appropriateness of its use (Manzo, 2004). It is suggested that the term is often overused and underdefined, and that social science almost never problematizes stigma. As such Manzo (2004) has suggested that there should be additional qualifications for stigma. These include: stigma must be knowable or known; stigma requires management; stigma attaches outcomes that are negative; those who are stigmatised are relatively powerless. This section seeks to explore the usefulness of stigma as a concept in facilitating our understanding of the experience of VAD recipients, and how this experience fits in with these factors.

For VAD recipients the visibility of the device can lead to concerns about how others may view them. In his seminal work on stigma, Goffman (1963) suggested that there are three positions that one can hold in relation to a stigma: the stigmatised, the normal, and the wise. The stigmatised are those who bear the stigma, the normal do not, and the wise are those amongst the normal whom the stigmatised accept as wise to their condition. He suggested that stigmatised individuals may experience concerns about how ‘normals’ will identify and receive them (Goffman, 1963). This was evident amongst the VAD recipients, during data

¹³ Etymologically the term stigma originates from the Greek period. In the cities of Attica and Athens out of populations of over 300,000 only around 40,000 were actually citizens. Over 100,000 of those who were non-citizens were slaves. These slaves were valuable property and would be tattooed by the Greeks to prevent them from escaping. The tattoo would be made with a sharp pointed instrument or a purpose made mark called a stigma, stig is the Greek word meaning ‘to prick’.

collection many interviewees demonstrated fear of experiencing stigma from these ‘normals’, expressing concerns about how others would react to the VAD.

At the beginning it was hard and I didn’t want to go outside, I was conscious that everybody was going to be looking and ‘ohh what’s that?’ ... [I] didn’t want to really talk about it... I just became fearful of going outside, and then having this as well made it a little bit worse. Like I say, if it was me and my husband or a member of the family I wasn’t as bad but to actually do it on my own, I wouldn’t. It did take a little while to build that confidence up, and I started going to rehab across at the hospital... the sister who runs it used to come and pick me up in a wheelchair and take me up....there used to be tears and head down, wouldn’t talk to anybody and very nervous and at this point I was the first VAD that they’d had in the group. (*Fran, 3 ½ years on VAD support*)

Concerns that others might stare at the device led Fran to fear going out in public, especially alone. Fran’s self-consciousness extended to attending the cardiac-rehabilitation group, and appeared to be compounded by the knowledge that she was the only one with a VAD. This again reflects the idea of the VAD recipients as having a special status, the presence of the VAD led her to perceive herself as different from those others in the group.

Concerns about drawing unwanted attention had a specific focus for many of the interlocutors, they were afraid of the device being misinterpreted as something dangerous or suspicious.

I used to have this stigma [of] people always looking at you, you know what I mean, because you’re walking around with a man bag and it’s like, I went out on New Year, I hadn’t been out for ages and ages and my sister and brother convinced me to go out and have a drink at the pub, and I just went out and there were loads of people there, friends and that, there was a couple of younger people staring at me all night and I had to change my batteries and so obviously when I opened it all up and changed the batteries they must have thought it was a bomb ‘cos they all started moving around and then back...people do look at you strangely when you go in shops and things ‘ohh what’s that on your side?’ and stuff like that. (*Stephan, 11 months on VAD support*)

Stephan recounts how he had to be ‘convinced’ by his brother and sister to go out, evidencing his discomfort with socialising in public. He specifically mentions that the night in question was New Year’s Eve, which is not an everyday night of the year to go out. New Year’s Eve carries special connotations and social places are likely to be busier than on any other night of the year, thus there may be greater pressure on the individual. Stephan’s describes how others ‘obviously’ would believe the device to be a bomb upon seeing its electrical nature, indicating that he views such suspicions as natural or normal, reactions that he expects ‘normals’ to have. Distinctions have been made between felt and enacted stigma (Scambler and Hopkins, 1986). Felt stigma is the fear of enacted stigma and a feeling of shame associated with the condition, whereas enacted stigma involves instances of discrimination against the individual on the grounds of their perceived unacceptability or inferiority. Stephan’s concerns could be seen as an example of felt, rather than enacted, stigma. However, one respondent gave an account of being expressly questioned about the nature of the device.

I even had one old lady one time think it was a bomb... she goes ‘what is it?’ and I go ‘it’s a heart pump’ so I had to explain to her what it was...that was actually on the train... ‘Cos we were just going to visit her [fiancée] nieces and nephews and we were just on the train, she wasn’t like panicky or anything about it, which was quite strange, she just came out with it. I think she jokingly said it, so that’s why I just explained to her what it was, but she was fine after that and most people know what it is, they are alright with it, I think it is more curiosity than anything because anything out of the ordinary people think ‘what’s that’s’, it’s just natural curiosity. (*Jack, 3 years on VAD support*)

Like Stephan, Jack appears to accept questions about the nature of the device as a natural part of living with the VAD, they are to be expected. Indeed, in today’s post 9/11 and 7/7 society there is often a sense of suspicion around ambiguous looking bags and electronic devices. Perhaps the questions and attention that the device attracts are an inevitable consequence of the uniqueness of this treatment. Strangers will express curiosity about the device; learning to manage these encounters is an important aspect of learning to live with the device. Stephan and Jack’s acceptance of this may be an important step in the development of a ‘normal’ life around the VAD.

Another aspect of the conspicuousness felt by the respondents in this study was the tendency to perceive that they would be viewed with suspicion when shopping. Several interlocutors provided accounts of being followed around shops by security staff.

Undercover police men in railway stations start following you, because they can see the cable coming outta you. And when you change a battery, if you change the batteries in a shop corner they think you're nicking stuff. But yeah, it adds to the fun. (*Matt BTT following chronic heart failure, 2 1/2 years on VAD support*)

As discussed in the previous chapter, VAD recipients have requirements in caring for the device, including the regular changing of batteries. This care taking must become a normal part of life for the VAD recipients. However, engagement in these behaviours when out in public is likely to increase the amount of unwanted attention that the device, and recipient, receives. Whilst Matt seems able to deal with this attention, stating it 'adds to the fun', for other less confident individuals this may act as a barrier to resuming a normal life with the device.

The external components of the VAD, and their visibility, appeared to impact on the manner by which the recipient is orientated to, both by close friends and family members, as well as strangers. This may potentially leave the individual vulnerable to experiencing stigma. The VAD could attract unwanted attention, leading the individual to feel conspicuous and uncomfortable when out in public. Such concerns could limit the extent to which interviewees felt comfortable in resuming normal daily activities.

7.5 Vulnerability of the VAD

One such concern that appeared to be a particular issue for the respondents in this study was the idea that the appearance of the VAD would leave them vulnerable to attempts to steal the device. Following implantation of the device VAD recipients are provided with a VAD bag developed by the manufacturers, in which to carry the external components of the device. The VAD bag has been developed so as to allow the VAD recipients to easily monitor the flow and battery levels of the device through the clear panel on the top, it also has cut out sections to accommodate the driveline and power cables. The VAD bag is very functional in appearance, similar to a video camera bag, an example is provided in figure 12¹⁴.

¹⁴ For clarity, this bag will be referred to as the 'VAD bag' throughout the rest of the thesis and any other as a 'normal bag'.



Figure 12: The VAD bag provided by the manufactures (HeartWare Inc. 2014)

Many interviewees felt that this similarity in appearance might lead others to misinterpret the device as something valuable and worth stealing.

Gary: Being out in public I was really conscious of it at first, now I've come to accept it you know.

HS: What were you specifically conscious of? It getting pulled?

Gary: It getting caught or somebody trying to pinch it, 'cos there's flashing lights you see 'cos I've been asked a load of times when I've been somewhere 'is that a camcorder?' or 'is that recording equipment?' you know you're going to a concert 'ohh you'll have to leave that'. (*Gary, 2 years on VAD support*)

Gary's account indicates that this fear was particularly acute in the period immediately following the VAD implantation, something that was echoed by many of the interviewees. Gary's concerns specifically appear to originate from experiences of being questioned about the device. These questions about the nature of the device led him to develop concerns that he may be vulnerable to theft of the device by others who have misinterpreted it as something valuable. Gary, in particular, may be more vulnerable to such negative interactions as he regularly attended music concerts where security staff are specifically on the lookout for recording equipment, increasing the likelihood of these interactions.

Fear of theft is an understandable concern for the interviewees as an attempt to steal the VAD could potentially damage the driveline and the exit wound, and disrupt the power supply to the pump. Some respondents worked to reduce this perceived threat by opting not to use the 'VAD bag', instead choosing to make the device look more innocuous.

I have got this bag I used to always put it in so it didn't look, 'cos it looks like a video camera, somebody tries to steal it or something you're absolutely knackered. You're in a bit of a pickle. (*Simon, 1 ¾ years on VAD support*)

The appearance of the VADs external components, and the 'VAD bag', clearly gave Simon cause for concern regarding his safety. Although it was unclear the extent to which Simon was concerned about muggings and theft before having the device implanted, whether he was predisposed to such concerns or whether these were a direct consequence of having received the device, it was obviously a pertinent issue for him. The VAD appeared to give Simon a greater awareness of his vulnerability and led him to view previously innocuous situations with greater caution and apprehension. However, there appears to be a temporal aspect to his concerns, they were more acute in the initial months living with the device. He 'used to' disguise the device, suggesting he no longer feels compelled to use this disguising bag, but is now happy to carry the device in the VAD bag provided by the manufacturer.

Concerns about attempted theft of the device are likely to be related to the recipients' awareness of the precarious nature of their condition and their reliance on the VAD to live. Their perception of vulnerability may be further enhanced by previous experiences of device malfunction.

Terry [Jan's husband]: As soon as you [un]plug.

Jan: I die, me.

Terry: I don't think all patients are the same, but she really does just go and then her lips start to go blue and she's like this [acts out becoming unconscious] and the thing's screaming and it's a panic situation...it's just again something you can do without to be quite honest.

Jan: It's happened four times hasn't it?

Terry: Four times we've had a controller fail.

Jan: Four times, and I just go as soon as he pulls that life line out of me, because that is my life line, he pulls the life line and I'll go [motions fainting] and as he said my lips are getting bluer and bluer and bluer, this is seconds. (*Jan, and her husband Terry, 4 years on VAD support*)

Jan and Terry's experiences of having a controller failure brought the reality of the device as a life-support machine into horizons of day-to-day meaning. Following a disconnection of the device, Jan's condition could become life threatening in a matter of seconds. As a result, Jan and Terry may perceive the threat of death as being more close to hand than those who have not had such experiences. The distress of these situations, on both Jan and her husband, is evident in the quote above.

The interviews demonstrated that the respondents had given thought to the different ways in which the external components of the VAD could be interpreted, and that this could leave them vulnerable. Fear of someone attempting to steal the bag is understandable given the intimate manner that it is attached to the recipient's body and its role in supporting the heart. Fears and perceptions of vulnerability may be compounded by personal experiences of controller failure where the flow of the device is interrupted that highlight the respondents' fragile grasp on life. Choosing to conceal the device, making it look more innocuous, may offer these individual a way of protecting themselves from such dangers.

7.6 Disguising the VAD

There has been a tendency for members of stigmatised groups to be portrayed as helpless victims (Link and Phelan, 2001); however, this is not necessarily the case, as was evident from those in this study. Interviewees appeared to utilise the resources available to them in order to resist stigmatisation and feelings of vulnerability. A stigma may be discrediting or discreditable (Goffman, 1963). A discrediting stigma is one that is immediately visible to others, whereas one which is discreditable has yet to be revealed. Visibility plays an important role in producing the negative social relations that the stigmatised have to endure (Crocker and Major, 1989, Jones et al. 1984). Those who are able to conceal signs of the stigma are thought to face less prejudice and experience fewer negative interactions than those whose stigmas are nonconcealable (Jones et al, 1984). However, these are not necessarily dichotomous categories; rather there may be a continuum of discreditability. Respondents in this study described choosing to disguise the VAD when out in public in order to minimise the relational impact of the device, turning the VAD from a discrediting to a discreditable stigma. The purpose of this appeared to be to avoid 'normals' becoming aware of the device.

Ned: I've gotta wear it [VAD] and most of the time it's under me coat, with a big coat on, it's under me coat nobody can see it anyway. And as for this cable here [driveline], going in, nobody sees that anyway. ... so the majority

of the time it's tucked away, you know, under a coat or something like that. But I haven't got a problem with it, no.

HS: What was your concern initially, just that people would stare or ask questions?

Ned: No, just if people think 'ohh what have you got there?' It's the same as before when I'd had it fitted I couldn't walk that far at all. I had a wheelchair if I was going for a walk along the seafront or something like that, people think 'why do you need a wheelchair?' I mean, 'cos you haven't got a plaster on your leg or a blooming arm off or something like that people thinking 'what are you doing in a wheelchair?' some people just don't realise, they think just take it for granted, they're alright so everybody else has got to be the same. But I don't have a problem, at first, but you get over it you know what I mean, now it's alright. No problem. (*Ned, 2 years on VAD support*)

Ned's concerns appeared to be focused on what others would think of the device, and as an extension himself. As VADs are a relatively new technological development that are only offered to a very small subset of those with advanced heart failure, they are relatively unknown amongst the general population. Generally, following VAD implantation recipients look and feel better, and it may not be immediately perceivable to strangers that they are unwell. However, while the heart failure may no longer be perceivable the external components of the VAD are, and their visibility could be considered discrediting. Ned suggests that the fact VADs are relatively rare might lead him to experience more negative attention than if he had a self-evident condition such as an amputated limb. He fears that he may be seen as underserving of the exemptions to social expectations afforded by the sick role¹⁵ because he does not appear outwardly unwell (Parsons, 1951). Consequently, VAD

¹⁵ The sick role (Parsons, 1951), enables individuals to bridge the period of incapacity enabling conformity within the deviance of illness. Whilst in this sick role the individual's everyday rights and obligations are suspended and these are replaced by a set of sick-role specific rights and obligations. The right to exemptions is met by an obligation to retreat from normal everyday life; patients are expected to isolate themselves from the healthy (Zick Varul, 2010). The sick role was originally constructed in reference to acute illnesses that are transient and its application to chronic illness has been questioned. The chronically ill individual has a strong incentive to return to normal role performance in spite of persisting illness, they must manage the competing expectations of the on-going sick role and normal everyday roles.

recipients could be thought to hold a special status, as dual citizens in the world of illness and the world of health. They are in a liminal state between health and illness.

Disguising the VAD took a number of forms including hiding the device under clothes, as described by Ned. However, adoption of a 'normal' bag rather than the 'VAD bag' was the preferred method for disguising the device for the majority of the interlocutors.

I would always, when I went out, I would put this in it [other bag]...I would put all of that in it and then I would put the green bag over my shoulder and you could hardly see anything at all, you didn't even know, because it was just a green bag and the fashion is that fellas carry a green bag, an army sort of bag, anyway nowadays, across the body, I could wear that and I wore that loads and loads of times, out and about, and I always took it out. I didn't feel confident wearing just this out [VAD bag]...nobody notices it at all, erm it [other bag] disguises it quite well. (*Simon, 1 ¾ years on VAD support*)

Simon states that no one notices anything unusual because it is 'just a green bag' suggesting that this bag, unlike the 'VAD bag', does not have other potential meanings attached to it. It does not attract unwanted attention from 'normals' because it is the 'fashion' for men to carry this kind of bag. Disguising the VAD bag by placing it in a 'normal bag' affords concealment of the device to a certain extent; however, it is not possible to conceal the device entirely.

A benefit of this practice of concealment was that it offered some control over the disclosure of their condition. Concealment and disclosure are complex and selective strategies of information management, giving the individual the autonomy to decide when and to whom they disclose their illness.

I put it all in just like a Fred Perry bag, that and all my spares, and then I didn't have anyone asking questions who I didn't want to ask questions like. I'll quite happily talk about it with people but you don't want to have ... 'why are you carrying a bag in a pub mate?' And it's like bugger off [laughs]. (*Grant, 2 ½ years on VAD support*)

The stigmatised may control the risk of being discredited by dividing the world into a large group to whom they tell nothing and a small group to whom they tell all (Goffman, 1963). Whom to disclose to, and how much, are important decisions in the management of a stigmatising condition. Those with stigmas may be unsure of whether to disclose their condition and to whom (Joachim and Acorn, 2000). The amount of choice that individuals

have about disclosing their status is related to the visibility of the illness. Individuals who have a visible illness may have less choice about whether or not to disclose their condition than those whose condition is invisible. Charmaz (1991) has drawn a distinction between two types of disclosing: protective disclosing and spontaneous disclosing. Protective disclosing is planned by the individual with the aim of controlling when and to whom their condition is disclosed. Spontaneous disclosure on the other hand is emotional and often related to shock and disbelief. In practice, protective disclosure may involve both concealment and disclosure. Grant's practice of disguising the VAD as a normal bag may be a form of protective disclosing. Evidently, there are some people from whom Grant would welcome and accept questions; however, this is likely to be a very small subset of people. Disguising the device allows Grant to avoid questions he may not wish to answer, as well as intrusions to his privacy. Goffman (1963) suggests that when amongst others a discredited person may feel that they are exposing themselves to invasions of privacy. The impact of intrusions from strangers may be particularly disruptive to younger VAD recipients like Grant, constantly reinforcing his 'stranger' status. Disguising the VAD may help him maintain his sense of identity as a 'normal' young man. Thus, disguising the VAD may be an attempt to try to lead a normal life and preserve a sense of self, which has been highlighted as a key aspect of men's experiences of chronic illness (Charmaz, 1995). Charmaz (2002) describes how chronically ill individuals may choose to partition their experience to some extent, allowing themselves to be sick and acknowledge suffering, but only in private places and close relationships. Furthermore, she suggests that over time the chronically ill individual can become a master at reading cues of how much to disclose about the illness and to whom. The more risks that they anticipate arising from telling, the more circumspect they will become about what they disclose (Charmaz, 2002).

The metaphor of 'coming out of the closet' has been applied to the management of discreditable information, using the example of epileptic patients (Schneider and Conrad, 1980). They suggest epileptic seizures may be seen as akin to involuntary 'faux pas' such as breaking wind or belching. The VAD recipients in this study may be seen to committing similar 'faux pas' when having to change the batteries or having the alarm going off in public. However, Schneider and Conrad (1980) argue that the assumption that a patient is either in or out of the closet and one follows from the other in a linear fashion, does not necessarily hold true. In particular, in the case of those with illnesses that are both visible and invisible, it is possible to be both in and out of the closet at the same time. Indeed, the VAD recipients'

practice of disguising the VAD may allow them to be both in and out of the closet at the same time.

It is possible to theorise the interviewees' accounts of disguising the VAD as attempts to 'pass for normal'. Passing is an identity management strategy (Barreto, Ellemers and Banal, 2006), originating from Garfinkel's (1967) essay about Agnes the transsexual's attempts to pass as a natural woman. Garfinkel (1967) defines Agnes passing as:

The work of achieving and making secure the rights to live as a normal, natural female while having continually to provide for the possibility of detection and ruin and carried on within socially structured conditions
(1967: 137)

Individuals engaged in passing try to conceal the stigmatising condition so that those who are unaware of their status will take them to be 'normal'. Members of a stigmatised group often have a choice of whether they wish to reveal their devalued group membership to others. Rather than disclosing, the individual may choose to pass as a member of a more positively valued group to avoid experiencing negative treatment. Alternatively, individuals can choose to engage in covering (Goffman, 1963). Unlike passing where the individual is engaged in an act of deliberate concealment, when covering the intent of the individual is instead to downplay the condition. Covering may minimise the effects and stress of having a stigmatising condition. According to Barreto, Ellemers and Banal, (2006), covering differs from passing because the individual is covering the devalued identity without necessarily making efforts to pass as a member of a more positively valued group.¹⁶

The interlocutors' narratives indicated that they routinely used humour to diffuse potentially awkward social interactions. This joking about and around the defect may be an example of covering, whereby humour is used to make 'normals' feel more comfortable.

Gemma [Ben's partner]: We make jokes about it now, just like go and plug yourself in, just like stupid little jokes like that

¹⁶ However, it might not be possible to cover without passing. An individual who is covering may be assumed by others to be a member of the more valued group. The example of sexuality is used to highlight this; if a homosexual individual chooses to cover their homosexual identity then others, on assumption, may take them to be heterosexual (Goffman, 1963).

Ben: Like ‘me phones dying, lend us a battery’ and things like that, and I don’t know, it helps you when your pals laugh away. (*Ben, and his partner Gemma, 2 years on VAD support*)

Joking about the VAD with his friends helped Ben re-establish his position within his friendship group. By using the VAD as an object of humour, he appeared successful in putting both himself and those who were wise to the condition at ease, diffusing any tension or awkwardness that might arise. Covering can confer joint membership, allowing the individual to fit in with ‘normals’ as well as with the group that is being stigmatised (Joachim and Acorn, 2000). Covering affords some control over social encounters reducing the chance of others making intrusions into their privacy as well as reducing the chances of experiencing discrimination.

An alternative reading of the VAD recipients’ practice of disguising the VAD is that it is an attempt to achieve a sense of cosmesis. The term cosmesis originates from cosmetic surgery and prosthetic limbs, referring to the preservation, restoration or bestowing of bodily beauty. Realistic looking but passive limbs may be preferable to functional but less aesthetically pleasing prosthetic limbs, as they allow the individual to maintain their humanness (Murray, 2008). One respondent in Murray’s (2008) study suggested that the importance of cosmesis was inversely related to an acceptance of their dependency on machines, those who had dealt with the amputation were comfortable with functional prosthesis that looked like a machine. VAD recipients, like those with prosthetic limbs, are dependent upon technology. The interlocutors reports of using ‘normal bags’ could be viewed as a discomfort with the nature of the VAD as a machine that was taking over a vital bodily function. The tendency to hide the VAD was particularly evident amongst those who had only recently been implanted with the device.

At first he wouldn’t go out would you, you’d have to have your jacket on... when we were away in France he’d have to have a jacket on to hide it and it took a long while for you to be able really to sort of accept that it was there. (*Gail, wife of Gordon 1½ years on VAD support*)

Gail describes the time it took for her husband, Gordon, to come to terms with the fact that the device was attached to him. Thus, the desire to disguise the device may be a manifestation of an inability to accept dependence upon the device. Indeed, those who did not feel the need to cover or pass appeared more accepting of their dependence on machinery.

Some of the VAD patients will come in and they'll have the belly belt on and they'll have t-shirts over it and all this...it's alright for them but I don't care, the worst case is that someone will think that I'm a poof, and that it's a man bag or something, you know what I mean, it's nothing. I never actually think right I need to hide it, it's there, and that's what keeps me alive and I don't care. (*Michael, 6 months on VAD support*)

Michael is aware of other's passing and covering behaviours, however as he is comfortable in his attachment to the device and its role in keeping him alive, he has no desire to engage in such behaviours. Furthermore, he does not perceive any negative outcome arising from the device being visible to others; he looks positively on the device as it is keeping him alive.

Attempts to disguise the external components of the VAD were common, particularly in the initial months after receiving the device. For the respondents, trying to pass as 'normal' was an attempt to avoid others discovering their discreditable identity. However, the need to disguise the device appeared to dissipate over time spent living with the VAD. This may be related to an increasing acceptance of the technology, its presence in their lives and their reliance upon it. Once the individual is comfortable themselves with the machinery, its attachment to their body, and its role in keeping them alive, they may no longer feel the need to disguise it from others and may feel comfortable using the VAD bag developed by the manufactures revealing the device and its technological nature.

7.7 VAD and gender identity

As discussed above, practicalities necessitate that VAD recipients employ a bag to carry the external components of the device. Some interviewees demonstrated concerns regarding the appearance of the VAD bag. However, for others it appeared that irrespective of the bag used a level of discomfort was experienced. The majority of VAD recipients interviewed were male; this is fairly representative of the population fitted with these devices (Özalp et al. 2014), at least from the implanting centre from which interviewees were recruited. The rest of this chapter of the thesis will discuss the impacts of the device on recipients' gender identity, specifically focusing on these male recipients.

Difficulties and discomfort in adjusting to the behaviour of carrying a bag were attributed to the fact it was a feminine activity.

Being a lady, girl, woman, a female whatever you want to be, you're used to having a handbag, so it's probably the same as that, it's weird for me...you're probably more used to it. (*Simon, 1 ¾ years on VAD support*)

Here, Simon openly suggests this aspect of living with a VAD would be easier to adapt to for female recipients. This may be true to some extent, those women who are used to carrying a handbag will probably find it easier to adapt practically to remembering to pick up the device and carry it with them. For Simon, this behaviour is 'weird' and unexpected, something which he did not anticipate having to become accustomed to. Whilst Simon focuses on the practical difficulties of adjusting to carrying a bag, others indicated that it was inappropriate behaviour for men. Carrying a bag caused them a level of discomfort, and could result in stigma from others.

We go to Scarborough in October and there's this pub we go in and this bar lady, bar women, says 'you look a bit strange, carrying your handbag with you'. (*Matt, 2 ½ years on VAD support*)

The disparaging intent of the bar lady's comment is evident in her use of the term 'handbag', used typically to refer to only women's bags. Experiencing a chronic illness can threaten masculine identities, potentially leading to identity dilemmas, which can be recurrent and current, like the illness itself (Charmaz, 1995). Men's masculine identities are a reflection of the lifelong participation in the gender order, taken for granted when things are stable. Suffering from a chronic illness may relegate the man to the position of marginalized masculinity, disrupting the individual's potential to fulfil traditional masculine roles such as those of hegemonic masculinity¹⁷ (Connell and Messerschmidt, 2005). From the interviews there was a sense that the need to carry the external peripherals of the VAD in a bag was incongruous with traditional perceptions of what it means to be a 'man' and appropriate male behaviour. Carrying the bag had the potential to be emasculating.

You're always thinking even if people aren't looking, it's daft stuff, like you don't like standing in a busy chip shop and all that cos you think 'ahh these youngens aren't going to know what it [VAD] is', they're just going to go 'ahh look at that poof with a bag on'. (*Ben, 2 years on VAD support*)

The behaviour of carrying a bag appears to be incongruent with Ben's identity as a 'Heterosexual man'. Courtenay (2000) suggests that if men and boys engage in social actions that demonstrate feminine norms of gender, they risk being relegated to a subordinated masculinity of a 'whimp' or 'sissy'. Such fears were certainly evident in Ben's narrative.

¹⁷ Hegemonic masculinity is the idealised form of masculinity at a given place and time, the socially dominant gender construction that subordinates femininities as well as other forms of masculinity. This reflects and shapes men's social relationships with women as well as other men.

Although, he presents these fears in a jokey manner it is clear that he had real concerns about how ‘normals’ would react and how this might influence how he was viewed as this was a topic that he returned to several time during the interview. It is likely that for Ben, and the other recipients, there are imbedded class and cultural meanings of masculinity and for whom and when it is appropriate to carry a bag. Social class positioning may both constrain and enable certain forms of gendered social action (Messerschmidt, 1993). Gender is a set of socially constructed relationships, produced and reproduced through people’s actions rather than two static categories of male and female (Gerson and Peiss, 1985). Furthermore, given Ben’s young age he may experience greater concerns about how others view him than older recipients. The relationship between doing health and doing gender has been investigated in teenagers with diabetes and asthma (Williams, 2000). Similar to VAD recipients, these are conditions that require a high level of self-care. Those in Williams’ (2000) study appeared to make efforts to keep their conditions outside of their social and personal identities. They viewed signs of their illness as potentially stigmatising and worked hard to pass, whenever possible, when in public settings. The ability of VAD recipients to keep their condition outside of their personal and social identities may be constrained by the external peripherals of the device.

7.7.1 Multiple masculinities

Receipt of a VAD appears to constrain the exhibition of masculine identities. However, the discussion of masculinity above relates mainly to a traditional view of masculinity or Hegemonic masculinity, and it would be dismissive to suggest that Hegemonic masculinity or traditional trait masculinity is the only type of masculinity that men may choose to adopt. Femininity and masculinity do not exist as two ends of single bi-polar dimension, masculine traits are not necessarily the opposite of feminine (Annandale and Hunt, 2008). The male gender role itself is a multifaceted construct comprising different components (Helgeson, 1995). Masculinity viewed from a social constructionist perspective is flexible, constantly constructed and challenged; gender is something which men ‘do’ (Addis and Cohane, 2005), and it may be best theorised as a verb rather than a noun. Furthermore, it has been suggested that men whose masculinity has been marginalised, compensate for their subordinated status by defying hegemonic masculinity and constructing alternative forms of masculinity (Courtenay, 2000).

Indeed, this appeared to be the case for many of those in this study. After a period of time spent living with the VAD several of the interviews had accumulated a wardrobe of bags in which to carry the device.

I've got millions, I've got a designer bag... me wife when I was in here...she came in, she says 'I've just been away and brought a designer bag'...I says 'right, I'm having one of them' and this nurse come back with her iPhone, she goes 'that's the one you want there' (laughs). So I went away and got one, bloody, great, big poof that I am...Ohh I've got millions, I've got a designer bag...I've got a proper designer man bag to put it in and I've got a couple of little bags and like a big canvas satchel...I've got me dress bags and me knocking around in bags. (*Gary, 2 years on VAD support*)

Gary had acquired a collection of bags to which he had attributed different functions. This collection included 'dress bags' and 'knocking around bags'. This behaviour suggest that Gary has moved beyond being embarrassed by the device, to seeing it as an extension of the self, as discussed in chapter six, and like the self it is dressed up or down as appropriate. Such behaviour is particularly interesting given Gary's social background. Gary was a working class man in his mid-50s, who before his illness had been employed in manual labour style employment. We might expect someone with a background such as Gary's to be concerned with the traditional masculine ideals of hegemonic masculinity. However, this does not appear to be the case, Gary appears to have developed his own sense of masculinity in which carrying a bag is an acceptable and appropriate behaviour. Furthermore, several interviewees revealed ownership of designer bags. These respondents drew pride from the fact that their bag is not just 'any bag', but one that is aspirational and desirable. Whilst the ability to achieve status from traditional gender forms may be problematic for male VAD recipients, as they are restricted in their ability to take part in traditionally gendered behaviour such as physical activity and drinking, the possession of these luxury brands offered them the opportunity to regain some sense of status.

The behaviour of carrying a bag appeared to be at odds with traditional masculine identities held by many of the respondents, and could leave them vulnerable to discrediting interactions. However, it appeared that over time the interviewees were able reconstruct their notion of masculinity and male identity. Taking pride in the type and brand of bag carried was one means of retaining a sense of status.

7.8 Conclusion

An important aspect of 'Being' a VAD recipient was learning to deal with the presence of the VAD and its impacts on social identity. Managing the visibility of the VAD was particularly

important as it has a far-reaching relational impact: on those who are aware of the VAD and underlying heart failure, the VAD recipient's family and friends and also on strangers.

The concept of stigma appears to give some insight into the impact on the VAD recipients' identity. The visibility of the device may lead them to feel self-conscious and conspicuous when out in public with the device, fearing the device may be misinterpreted as something suspicious, such as a bomb. However, respondents' narratives indicate they personally endeavour to deal with and negate these issues. The sociological concepts of passing and covering offer us a means of understanding these behaviours as attempts to avoid being discredited. Furthermore, participants appeared to be successful in these endeavours. Over time, these concerns appeared to dissipate; VAD recipients come to accept the changes in their appearance and identity conferred by the VAD, and the reality of their dependence on the machinery to live. Like those in Murray's (2008) study, this reduction in the need to disguise the mechanical nature of the device may represent an increasing acceptance of their reliance on the VAD as a prosthetic organ.

The behaviour of carrying a bag appeared to be at odds with traditional masculine identities. Such concerns may have been particularly acute for the respondents in this study who were mostly middle-aged working class men from the North East of England. However, there are multiple forms of masculinity, and the respondents appeared to be able to successfully develop new masculine identities of which carrying the VAD was part. This chapter introduced the relational impact of the VAD; this will be expanded in the next chapter, which discusses further the impact of the device on recipients' social interactions. This includes the development of new and valued connections based on one's new identity as a VAD recipient.

8

The VAD and its Impacts on Social Relations and Communities

Chapter 8. The VAD and its Impacts on Social Relations and Communities

8.1 Introduction

The previous chapters discussed how receiving a VAD can be experienced as an extremely disruptive event in an individual's life. However, as humans are social creatures whose lives are inextricably interwoven with those around them, it is important to look beyond the individual and their partner. Disruptive events, such as chronic illness, will impact on social roles and responsibilities and connections with others. Furthermore, an individual's social resources and position will shape how they respond to the challenges posed by chronic illness (Ziebland and Kokanovic, 2012). This chapter focuses upon the social relations and communities of those living with VADs. This includes a discussion of how social roles change following the development of advanced heart failure and the implantation of a VAD. Attention is also turned to the communities that exist amongst those living with VADs, how these are developed and maintained, and their impact. I discuss these communities in relation to three domains: experiential knowledge and understanding; comparisons; and the impact of death within the group. Particular attention will be given to the positive and negative effects of these communities.

8.2 Impact on family and social relations

8.2.1 *Disruption to normal social roles*

As discussed in chapter 5, the experience of being diagnosed with advanced heart failure and receiving a VAD is a major event in an individual's life and may be experienced as a form of disruption to the natural order of life this is known as biographical disruption (Bury, 1982). The natural order is often assumed to be cyclical: children are looked after by their parents, these children will grow up to have children of their own and look after their parents in their old age, and in turn their children will look after them as they age. However, this natural order can be disrupted by the diagnosis of a serious illness. The type of disruption experienced may vary according to the individual's stage of life, as age carries social meanings and temporal age-graded perspectives (Elder, 1994). Respondents in this study described different levels of disruption to their social roles and relationships depending on their stage of life. Younger recipients focused their accounts upon the disruption caused to their parents and partners. Indeed, for parents of young VAD recipients the perception of a violation to the natural order may be particularly acute. It is widely accepted that the loss of a child, including adult children, is one of the most devastating and life defining experiences a parent can face (Coleman and Richmond, 2008, Gorer, 1965). Often, for the younger interviewees it was

witnessing the impact on their parents that really brought home the reality of the severity of their condition. Whilst respondents did speak of the pain and fear felt by their parents, some also alluded to the fact that the experience could also enhance the relationship.

I've noticed since I've become ill me and my dad seem to have got a lot closer and he found it quite difficult at first to adapt to it, cos no parent should see their child lying in a hospital bed and being as ill as I was, he actually did break down a couple of times. (*Jack, 3 years on VAD support*)

It could be argued from Jack's account that his father's response to the possible threat of losing him resulted in a breach of the familial norms that had been established between them, in that he had actually broken down in front of Jack on more than one occasion. This emotional vulnerability may have been an important aspect of fostering a stronger and closer relationship between father and son.

For those with VADs who were parents themselves, the focus of their accounts was often on the disruption to their ability to engage in the perceived roles and responsibilities of family life.

I want to go on the boat with the bairn [daughter], the hire boat, but I can't do that, I can't play with the bairn properly, she can't jump on us, stupid little things, it's the small things that you wouldn't have thought would get to you that do...it's the little things that get to you. (*Michael, 6 months on VAD support*)

For Michael, receiving a VAD resulted in the loss of fleeting moments of parenthood. He feels that he was not able to play 'properly' with his child, in that, through living with a VAD, both he and the child are lacking a very specific and precious form of interaction. The frustration of Michael and other parents with young children may stem from preconceived ideas of what it means to be a 'good parent', ideas of a 'good' father include being able to physically engage in play. Similar, feelings of inadequacy have been found amongst fathers with arthritis who are unable to fulfil the physical demands of parenting (Barlow et al. 1999). In addition Fran, a female VAD recipient with young children, expressed upset and guilt that she had been unwell for the entire lifespan of her younger children, they had no memories of her beyond 'being ill'.

Guilt at not being able to fulfil social roles was also evident amongst older interviewees with elderly relatives.

My wife's mother is still alive but she's very frail now...we don't see a lot of her, although we speak a lot by phone...I feel guilty in a way, which I know I shouldn't but you can't turn your feelings off, you can reason, but the feelings stay, but I can't do enough to help her, like going and seeing her. *(Albert, 1 ½ years on VAD support)*

What appears key to Albert's experience, and the cause of his distress, is his inability to be physically there for his mother in law. Whilst Albert was unable to travel due to complications with the VAD, his wife also had medical problems of her own meaning she was unable to manage the journey alone. Although he and his wife were able to maintain contact and communication with the mother, the VAD prevents them from being physically present. There appears to be a distinction between communication and physical co-presence. While communication is important, it does not ease the desire to be present together. Albert's guilt is likely to be compounded by the fact that not only is he not able to visit his mother in law but neither is his wife.

As such, living with a VAD appeared to disrupt individuals' ability to fulfil perceived roles and responsibilities in family life, resulting in feelings of guilt or distress. However, positive effects were also evident, as the distress experienced amongst family members and friends at the potential loss of the individual could foster the development of stronger family ties. Understanding and support from family members and friends is likely to be key in minimising the distress and guilt caused by the disruption to social roles.

8.2.2 Family support

Respondents' accounts suggest that there was a great deal of variation in the manner in which families and friends reacted towards the device and the level of support that was offered. Many of the interlocutors described networks of supportive family and friends, who helped with demands such as childcare, but not all were so fortunate. Some interviewees expressed disappointment at friends and family who appeared to be reticent to even acknowledge the existence of the VAD.

Me brother's reasonably okay with it 'cos he's got a disabled wife whose had problems with diabetes and really bad infected feet and things like that over the years...so he understands it and knows it's my box that keeps me alive and this, that and the other. And my sister basically can't cope with anybody being ill, so she knows about it, but she doesn't want to talk about it. *(Fred, 3 years on VAD support)*

Fred's bother is presented as the more understanding of his siblings, yet he is still only 'reasonably okay' with the situation. Furthermore, the description of his brother's understanding as '[he] knows it's my box that keeps me alive and this, that and the other' potentially suggests a rudimentary understanding of the device and what it does, which may also be shared by Fred himself. The lack of support proffered by Fred's sister appears to be neither personal nor particular to Fred and his current situation. She is presented as being unable to cope with 'anybody' being ill.

For some respondents the experience of illness and receiving the VAD appeared to be marked by little, if any, familial support. Following his illness and the VAD implantation, Darren and his wife Carole had experienced a reduction in their social circle, and in particular felt unsupported by their daughter Marie.

HS: Do you have other support from your family?

Darren: Not really

Carole [Darren's wife]: I don't think they really understand to be quite honest, do they?...You've just got to get on with it day to day, just the two of us.

Darren: They've got their own families now, that's what happens...

Carole: But she [Marie, daughter] doesn't give you support really does she?

Marie just finds a problem and if you've got a problem Marie just isn't, she's not sympathetic, so there's no point really saying things to her.

(Darren, and his wife Carole, 3 years on VAD support)

Whilst it does not appear that Marie specifically has a problem dealing with, or talking about the VAD or her father's condition she is positioned as being generally unsympathetic, and unable or unwilling to provide them with support. The emotional impact of the situation, particularly on Carole, was evident during the interview where she broke down in tears at several points. Darren and Carole's narrative was marked by a strong sense of isolation, and family members, friends, and even the clinicians were positioned as unsupportive. In addition, their encounters with other VADs recipients had reduced over time spent with the device. Whilst they used to run into a woman who was a similar age, from the same part of the country, who had received the device around the same time they had not seen her for some time, it is quite likely that she had since passed away. While Darren and Carole did not

actively try to maintain this contact outside of the hospital, it appeared to be a valued aspect of their clinic visits and was something that they missed.

Lack of support from family members and friends appeared to be an issue faced by some of the VAD recipients and their partners. A common criticism that the interviewees attributed to these unsupportive others was a lack of understanding of what the VAD recipient, and their partner, were going through, that there was almost a failure to acknowledge the severity and difficulty of their situation. However, as those with VADs are very unique others who are not directly involved may indeed be limited in their ability to understand the experience¹⁸.

Furthermore, those with VADs may also be limited in the extent to which they can convey what it means to 'Be' a VAD recipient to others. As in life, we are all limited in our ability to truly convey our experiences to others, the language we use to describe our experiences will ultimately substitute itself for the experience we are trying to describe (Van Manen, 2006). However, other VAD recipients and their partners who have experienced life with the device may offer some understanding of what it means to 'Be' a VAD recipient.

8.3 VAD communities

The section above described the impact of the VAD on recipients' existing relationships. However, other VAD recipients offered the opportunity to form new, and valued social relations. Many respondents described a sense of unity and similarity with others living with VADs. There are several occasions when VAD recipients may encounter each other, at arranged meetings with those living 'successfully' with the device prior to implantation, whilst in the hospital as an inpatient, and at clinic appointments. There appeared to be a tendency for VAD recipients to be drawn together whilst in the hospital, and time between appointments was utilised as an opportunity to socialise. This behaviour was also something the interlocutors also recognised within themselves.

We're like a gang we stick together. Aye, like if you come to the clinic we all sit together or if there's any 'dos' all the VAD people stand together.

(Gary, 2 years on VAD support)

Gary indicates that there is a sense of community between those with VADs; they are drawn together by this device that they share. However, it must be noted that not all of the

¹⁸ The very, small number of individuals fitted with VADs means these devices are not commonly known of or understood amongst the general population.

interviewees sought or valued this notion of community. Some expressed no desire to socialise with others who were living with VADs.

I don't come into contact with them, and to be honest the fact that you've got a VAD is not really the sort of thing that would make you want to socialise...it's like anything else, if I'd broke my leg and somebody else broke their leg, does that mean we've got anything else other than that in common. (*Albert, 1 ½ years on VAD support*)

Albert rejected the notion of the shared experience of having a VAD as a basis for a sense of community. He chose not to seek out others with VADs and described efforts to avoid conversations that were centred on swapping and comparing illness stories as this held no interest for him. It appears that for Albert, neither the VAD nor heart disease were integral to his sense of identity, and as such did not want to be defined by them. Through Albert's comparison, he rhetorically marks a shared illness experience as not a sufficient basis for making social connections with others. Similarities can be drawn to cancer patients who describe efforts to avoid socialising with others with cancer (McCaughan, Parahoo and Prue, 2011).

8.3.1 *Experiential knowledge and understanding*

For the majority of interviewees the VAD community appeared to be a source of social support. One respondent also described having contributed to an American online forum for those with VADs. However, as he was the only respondent to refer to using online support groups it is unclear to what extent these were used by the participants in this study. Thus, this thesis is not the appropriate platform to discuss the benefits or drawbacks of this form of social exchange. The most obvious example of a social support group from the data was amongst the five or six individual's with VADs who lived locally to the hospital. These individuals attended the local cardiac rehabilitation group together and organised monthly social events involving partners and family members. The VAD appeared to be the common factor that initially bonded these individuals.

[talking about the rehabilitation group] When we started all the seats were in a circle, we [VAD patients] always used to end up sitting together and it wasn't planned or anything and then obviously you start comparing or talking about different experiences...so I went from feeling as if I was on my own to then, well actually there's quite a few people who have got that [VAD] people from all different ages...but we've all got this in common

and you know we have a laugh, we text each other and you know you form a bond, a very close friendship with them, because you know exactly what they've gone through and how it feels to have this and nobody else can say that...we do sort of click together just because of this one machine, you know so you do make some good friends. (*Fran, 3 ½ years on VAD support*)

Meeting other VAD recipients appeared to be an important transition in Fran's experience, allowing her to move from feeling isolated to being part of a community. Similar effects have been observed in a review of the impacts of online support groups, which found that reading about other patients' experiences could reduce feelings of isolation (Ziebland and Wyke, 2012). Similarly, fellowship and support appeared to be an important component of the social network of VAD recipients. Camaraderie has also been described amongst those living with motor neurone disease, and was experienced just by being in the presence of others who understood what it is like to live with the condition (Locock and Brown, 2010). Furthermore, contact with those who share the same diagnosis has been found to engender positive experiences amongst those living with other chronic illness (Isaksen and Gjenedal, 2000).

Encountering others who understand their experiences may be a key event in 'Being' a VAD recipient. VAD recipients have transitioned from having a relatively common condition, advanced heart failure, to being in a very unique group, with only 600 having been implanted in the UK since 2004, and less than 200 individuals currently on VAD support (NHS Blood and Transplant, 2015b). When experiencing common health problems we have a wealth of lay experience and knowledge to draw on which has been built up over our lives. However, this knowledge is not available upon encountering a new problem; this may lead to a desire to know how others respond in the same situation (Gabriel, 2004). For those living with VADs it is only other recipients that can provide this information, they are the only ones who possess an understanding of the experience. Nagel's (1974) philosophy of consciousness states that whilst we may be able to imagine the subjective experience of another organism, we can never really know, we can only imagine from our own viewpoint¹⁹. Thus, it might be possible to imagine what it is like to carry a VAD bag, but unless experienced it can never really be understood what it is like for your life to be dependent on the device to live, and to live with the fear of the device failing. However, if we follow Nagel's (1974) argument to its logical

¹⁹ Thomas Nagel (1974) suggested that it is impossible to understand the subjective phenomenological experience of others. The example of a bat was used to highlight the impossibility. Any attempts to understand the subjective experience of a bat will come from our own point of view. Although we can imagine what would be like for us to be a bat, we can never really understand what it is like for a bat to be a bat.

conclusion, no one person with a VAD could completely understand the phenomenology of another person with a VAD. Yet, they possess more experiential knowledge than those without VADs. Experiential knowledge is defined as knowledge gleaned through personal experience with a phenomenon rather than truth that is acquired by discursive reasoning or observation (Borkman, 1979). Borkman (1979) refers back to the Latin proverb ‘Ruperto experto credite’, which translates as ‘Believe Rupert, who’s been through it’ (446). Experiential knowledge is holistic, encompassing the total phenomenon as it is experienced, which is distinguished by individuals from their common sense viewpoint. This experiential knowledge of other VAD recipients was highly valued and was at times afforded greater importance than the expert knowledge of clinicians.

It’s one thing speaking, to you know, like a psychologist or you know, someone like you, or you know a doctor or nurse, but I found it a lot better talking to someone whose actually been there and done that, whose actually gone through the experience themselves. (*Jack, 3 years on VAD support*)

The understanding offered by those who also had VADs was something that the interviewees could not get from anybody else, including clinicians. Amongst parents of children with a genetic condition information given by other parents in online communities was valued over that of the doctors because it was information combined with a personal stake (Schaffer, Kuczynski and Skinner, 2008).

Contact between VAD recipients was to some extent encouraged and enabled by clinicians, who arrange for individuals living successfully with the device to speak to potential recipients to provide a ‘realistic’ view of what life with the device would be like. This indicates that professionals also place a high value on experiential knowledge, incorporating it into the organisation of care. For the majority of respondents the first encounter with someone living with a VAD was before they had received the device themselves. As VADs are relatively new, few of the respondents had any knowledge or experience of the device before being offered one. Being able to physically see someone who was living successfully with the device appeared to be an important step in understanding what the future may hold.

Michael: I was in a good few weeks waiting because I had a chest infection and they had to get my weight down and water off and I met an Irish lad on one of the wards, on ward 24 and as soon as he walked in I was like ‘ohh I want to ask you some questions about your VAD’ and he like encouraged us

really, because he would like tell us how much better he was doing, he was cycling on a bike, doing all sorts

Kelly [Michael's wife]: Changed his life didn't it

Michael: Changed his life and from then I was like 100%, hoy [put] it in.

(Michael, and his wife Kelly, 6 months on VAD support)

For Michael, the experience of meeting another VAD recipient appeared to allay any fears he had about living with the device. Encountering others who offer a positive account of life with the device may be an empowering experience, fostering hope of the possibility of a positive life with the device. A similar effect has been noted amongst cancer patients, where contact with others at a support group has been found to result in the realisation that 'you are not alone' and it is possible to cope with the illness (Ussher et al. 2006).

Whilst exposure to other VAD recipients may indeed be beneficial, it may be the perspective of the individual that one is being exposed to that is important. A number of interviewees emphasised the importance of being exposed to those who were positive about life with the VAD. Exposure to those who were faring well rather than poorly seemed particularly important in the initial stages of life with the device.

It's important to listen to the positive people, there was a negative gentleman on the ward and you just wanted to say 'shut up, we don't want to hear it' n obviously he was like, 'cos he'd had bad experiences with his but at the time Paul didn't need to hear it, n it was just reassuring him, saying 'listen to the chap next to you not the guy in front of you' ...that was a bit, I think, upsetting for me, when someone was being so negative. *(Hannah, 4 months on VAD support)*

Exposure to negative experiences and viewpoints appeared to be particularly threatening in the period immediately after implantation. This suggests a temporal element regarding information needs, that they may change over time. Hearing positive accounts of life with a VAD may alleviate fears about what the future with the device may hold, offering those who are living with uncertainty, the hope that a more favourable future is in reach. This may act as a motivator for those recently implanted with a VAD that they too will be able to achieve positive outcomes for themselves, offering something to work towards. Exposure to positive perspectives may foster hope for the future, whilst negative experiences may nurture concerns about the condition worsening or potential complications. Indeed, amongst those with cancer,

contact with persons with the same disease who were more ill was found to result in negative affect (Wood, Taylor and Litchman, 1985). Furthermore, cancer patients have been found not to actively seek out information about less fortunate others, viewing those who provide negative stories as unhelpful, often attributing morbid motives to the storyteller (Taylor and Lobel, 1989). Likewise, Hannah, in the quote above, appears to question the motives of the gentleman who was telling them of his negative experiences with the VAD, implying that he was being selfish for not considering the impact that these stories would have on her and her husband.

Some respondents reported an awareness of the impact that their own experiences may have on others. They could position their own experiences on a positive to negative spectrum and perceive whether they would be beneficial to others.

As far as I'm concerned I think it's pointless telling people what's happened to me because that'll only instil fear in them...I wouldn't want to tell a new patient...this has happened to me, that's happened to me, the other's has happened to me, in the same way I wouldn't want to know the bad things that's happened to other patients. (*Ian, 7 months on VAD support*)

In contrast to the gentleman encountered by Paul and his wife, who appeared unaware or unconcerned about the impact of his story on others, Ian demonstrates a respect for others with his awareness of the effect that his negative experiences could have. It appears that contact with others may play a role in the adjustment to living with the device, and VAD communities may facilitate the sharing of information around successfully living with, and managing the VAD. The stigma literature suggests that those with 'spoiled identities' may be motivated to seek out 'sympathetic others...who share the stigma', and this contact can be used as a source of practical and social support, through which the 'tricks of the trade' may be learnt (Goffman, 1963:31-32). Furthermore, the sharing of this experiential knowledge may lead to the development of a communal body of knowledge which exceeds the boundaries of individual experience, known as 'experiential expertise' (Caron-Flinterman, Broerse and Bunders, 2005). Certainly, sharing of tips around managing the VAD day-to-day appeared to be a valued aspect of contact with other VAD recipients.

Some people are very knowledgeable about them, very helpful, and it's really practical stuff, you know, that they can be very helpful with, there's one chap, who's devised this thing the DAVE clip...it's just a fantastic idea if you drop the VAD or something it doesn't pull the wire 'cos you connect

it to yourself. So things like that have been great. (*James, 11 months on VAD support*)

James indicates that for him it is the practical aspects of living with the VAD that other recipients can offer assistance with, rather than emotional support. He specifically refers to an invention of one the group, which clipped the VAD to the individual's belt loops holding the device in place so it would not pull on the driveline if they leaned forward or the bag's strap slips from their shoulder. This process of information sharing may spare some of the recent VAD recipients some of the time-consuming and frustrating work of trying to fit the device into their day-to-day lives, enabling them in the process of normalising the device.

Further, taking on this role of 'experienced patient' and talking to VAD candidates appeared to help some individuals come to term with their own illness experience.

My transplant co-ordinator George, has got us to go and speak to other patients, and I find that it doesn't just help them it helps me as well, talking to them because...it's like looking at me three years ago...it actually helps me to understand what I was going through as well...there is a woman who I went to talk to and she'd just been told the same news as me, like you need a VAD and if you don't get it then obviously things are going to happen, and she was in such a state, but after talking to me she just seemed to pick up and it was quite strange because she give us a big cuddle and said 'thank you very much', and I've never really had someone genuinely mean it.

(*Jack, 3 years on VAD support*)

However, Jack continues to be vague regarding his closeness to death 'if you don't get it then obviously things are going to happen', suggesting that the reality of how near to death he was may be something which he has still not totally accepted or is uncomfortable discussing.

Helping others by sharing one's experiential knowledge may also aid in the establishment of new valued identities. The experience of chronic illness can result in the crumbling away of valued self-images without the development of new ones that are equally valued (Charmaz, 1983). Using personal knowledge of the illness and life with the device to help others may enable the development of new valued identities, through being positioned as someone who can (genuinely) help those who are going through the same experiences. This certainly appeared to be the case for Jack, who spoke of his desire to find a role where he could be actively involved and supporting future VAD recipients.

Sharing knowledge about the day-to-day realities of living with a VAD appeared to be a particularly valued aspect of contact between VAD recipients. The benefit was endorsed to some extent by the clinicians who arranged meetings for VAD candidates. Recipients also valued the new identity that this sharing of information afforded, helping to replace those that may have been lost following the development of the chronic illness. Another function of contact with other VAD recipients was the ability to see how others were faring with the device.

8.4 Social comparisons

Comparison of oneself against others with a VAD may be used to ascertain how one is coping with the device. The practice of ascertaining one's position by comparison with similar others was discussed in Festinger's (1954) social comparison theory. Festinger (1954) proposed that social comparisons occur between similar people or between people who are experiencing similar problems. Comparisons allow individuals to be able to evaluate their position, allowing them to ascertain how well they are faring compared to others. Three main motives have been suggested for making social comparisons. Firstly, to achieve an accurate self-evaluation; secondly, to maintain a positive self-image; finally, the desire to self-improve. The motive behind the comparison will influence with which others they chose to compare themselves (Leventhal, Hubson and Robitaille, 1997). Social comparisons are thought to be particularly prevalent in situations of fear and uncertainty (Festinger, 1954), where those who are under threat may demonstrate a strong preference for evaluation against less fortunate others (Taylor and Lobel, 1989). Comparing oneself against less fortunate others is known as a downward comparison. By looking to someone who is worse off, a more positive view of one's own situation can be achieved. Thus, downward comparisons may be a defensive tendency (Wills, 1981). However, in the literature exploring comparisons amongst cancer patients there is some disagreement in the direction of comparisons that patients make. Whilst Taylor and Brown (1994) suggest that those with cancer chose to consistently evaluate their condition against less fortunate others, McCaughan, Parahoo and Prue (2011) suggest that cancer patients engage in all types of comparisons, sometimes even within the same case.

Downward comparisons were evident amongst the respondents, many of whom chose to compare themselves with others who had experienced a greater number of problems with the device. This was particularly evident in the interview with Fred and his wife Nancy.

Nancy: I suppose thinking of other people on VADs...

Fred: We don't spend much time in hospital compared with other people on VADs. I mean sort of, there's Ian... a bed across from me, I mean he's been in since basically he had his VAD put in, so he's been in for twenty weeks or something, 'n he's just like, it's got to be really doing his head in.

Nancy: So we're in fact when we look back, we've been quite lucky 'cos we've been able to stay at home an awful lot more than a lot of other patients, haven't we. (*Fred, and his wife Nancy, 3 years on VAD support*)

Fred and Nancy reflect that their situation could be worse, others are less fortunate, and this allows them to be positive. They are fortunate within a context; there is always someone who is worse off. Positioning oneself as better off than others and reporting this in a positive manner may be an example of hope work. Hope work is where the medical identities' of the individual are explicated in terms of the hopefulness of the situation (Perakyla, 1991). A metasynthesis of hope in older adults with chronic illness, suggested that there were two main overlapping processes at work, transcendence and positive reappraisal; these were integrated in hope as 'transcending possibilities' (Duggleby et al. 2011). Sufferers of chronic illness strove to find meaning and purpose; positive reappraisal involved the discovery of positive possibilities following re-evaluation of hope in light of the illness. Focusing on an aspect of their lives in which they are better off than others, such as being able to be at home, may be an example of positive reappraisal, allowing Fred and Nancy to remain positive about their situation.

The focus of comparisons is not always directly related to health status, and may refer to other aspects relating to life with the VAD.

[I'm] really lucky that I live so close to the hospital and I kept thinking 'Ohh God, there's people that have come from Ireland and all over Scotland, Yorkshire', I can just...within ten minutes I can be here...it took a little while but I could start seeing the positives. (*Fran, 4 years on VAD support*)

Being in close proximity to the hospital may alleviate concerns about living at home with the VAD, offering security through the knowledge that expert support is available close to hand. There appears to be a temporal element to these comparisons, it takes time to begin to see the positive aspects of one's experience and begin to see oneself as comparatively better off. Morse and Penrod (1995) discuss the temporal element of hope, suggesting that in order to achieve acceptance following a life altering illness or event, the individual must have

experienced suffering. Development of hope involves continually monitoring for signs that may reinforce goals.

Interestingly, a number of the downward comparisons made by respondents positioned their experience as being easier than all others living with VADs.

It's [a] fantastic bit of kit, but then I realised it was a fantastic bit of kit for me. But not for everybody else, 'cos everybody I talked t' they've all had infections, they've all had clots, water retention, 'n stuff like that. Some've had the VAD changed. So, I just say for me personally, it was, is a good bit of kit but it's not for everybody. But for me it's alright. (*Matt, 2 1/2 years on VAD support*)

Rather than worry about potentially experiencing the same outcome, Matt uses others' experiences to reflect on how lucky he is. This may be an example of illusory superiority, a term first developed by Van Yperen and Buunk (1991 cited in Hoorens, 1992: 117) to refer to a cognitive bias whereby individuals overestimate their positive qualities and underestimate their negative. Over the time spent living with the VAD Matt had experienced numerous complications, including several driveline infections, as such it is unlikely that every other patient he encountered had experienced more problems. In addition, Matt may chose to focus on those whom he views as faring worse, as a stratagem for remaining positive about his own illness situation. The adoption of this positive stance may be an example of the societal expectation we have that even those facing serious illness, present a positive outlook to the world. In addition, the motives²⁰ for these positive accounts²¹ should be considered. Having a positive account of one's situation may be particularly relevant when presenting the self to

²⁰ Motives have been defined as 'the terms with which interpretation of conduct by social actors proceeds' (Mills, 1940: 904). Motives are a procedure for organising an historic and regular interactional future (Blum and McHugh, 1971). A motive is a collective procedure for accomplishing social interaction, it allows for linking acts and social rules to create a collection of social actions which observers will view as 'members' or 'membership'.

²¹ Scott and Lyman (1968) suggests that there are two types of accounts: excuses and justifications. When making a justification one accepts responsibility for the act in question, but there is a denial of its pejorative nature, in essence the individual denies wrongdoing. Whereas, an excuse is an account where one admits the act in question is bad but full responsibility is denied. The purpose of a justification is to neutralise an act which is called into question. In justifying an act, one is asserting its positive qualities, despite claims to the contrary.

others. Accounts may be used in the interview setting by respondents keen to show themselves in a positive light, as someone who is grateful for the device and is trying to make the most of their situation. We live in a culture where it appears that there is a moral responsibility to appear positive and to be 'looking on the bright side'; those who fail to do so could have negative moral connotations applied to them. For example, news reports of persons living with cancer often involve the construction of a narrative in which the cancer experience is depicted as meaningful, how journalists think these stories should be produced (Seale, 2002). Furthermore, context may play an important role in the construction of illness narratives. Indeed, this feeling of moral responsibility may be heightened by the research setting in which these interviews were conducted.

Not all of the respondents shared the view that comparisons to others were a useful practice.

HS: Did you look for information about other patients?

Lyn: No, he wouldn't, he wouldn't be that way he's more into...

Ian: The way I look at it, everybody's different (Lyn: yeah), nobody's the same. So you know, what happens to one patient probably, definitely wouldn't happen to another, you know there's not one patient the same.

(Ian, and his wife Lyn, 7 months on VAD support)

Unlike the interviewees above, Ian uses a different approach, rather than compare himself to others, he stresses that everybody is different, suggesting comparisons are futile as they will not provide any information regarding potential outcomes. In addition, focusing on the differences between individuals may allow one to distance oneself from those faring poorly, countering concerns that may arise. In some respects, Ian's protestations of being unique could be considered accurate, as he had encountered various problems resulting in him remaining in hospital for the majority of the time he had been living with the VAD.

Lyn [Ian's wife]: He's baffled the doctors why he keeps needing UF [ultrafiltration] he's the only patient

Ian: I'm the only VAD patient on (Lyn: constant) regular UF like that'. *(Ian, and his wife Lyn, 7 months on VAD support)*

However, comparison talk still appears to be central to making sense of the situation; this was achieved by comparing one's own situation against the norm. A sense of being unique can only exist as a result of a comparison against the norm. Thus, even though Ian posits he and others with VADs are not comparable and emphasises the pointlessness of comparisons, it is

evident that he and his wife still engage in comparison talk. As such, VAD recipients could be considered to be 'differently the same'. The concept of being 'differently the same' has previously been explored in a study of individuals with motor neurone disease and Parkinson's disease (Mazanderani, Locock and Powell, 2012). This concept suggests that those with the same condition can be at one and the same time both different and the same. Constructing one's position in this manner may allow some protection against distress encountered by contact with those faring worse whilst also allowing positioning of oneself against the norm.

Comparing oneself to others with VADs appears to be a useful tool for many of those living with the device. In particular, the process of comparing oneself to others who were worse off appeared to allow the individual to feel better about their own situation. However, this does not appear to be a linear relationship, if the object of the comparison dies this does not result in positive affect.

8.5 Deaths within the VAD group

The death of an individual with a VAD had a great impact on all those around them, including other individuals living with the device. Many of the interviewees spoke the impact of the death of other VAD recipients, often individuals they had come to think of as friends. Amongst cancer support groups, the progressive illness and death of a member has been described as one of the most difficult challenges faced by the group (Ussher et al. 2006). A similar impact was evident from the respondents in this study, and the upset appeared to have two levels, firstly, grief at the death of a friend, and secondly, fear of suffering the same fate.

I've actually had, unfortunately, two people who've died, one of my friends Andy... what I found hardest, because I'd met his family, I'd met his daughter and his two granddaughters and he'd waited so long for a transplant but then he died a couple of days later... they're not allowed to tell me the full story, but just bits of information I've got, his body rejected it and he was too weak, but there was Craig who was from the same area as me... unfortunately he got a bad infection as well and he died... losing those two people was a bit hard to deal with. (*Jack, 3 years on VAD support*)

Jack orientated to the intimacy of having met the extended family of Andy, going beyond partners whom you may expect to meet at clinic appointments and on wards accompanying the individual with the VAD: which serves to present a 'deeper' level of friendship developing with Andy, he was not just a causal acquaintance. Interestingly, Craig is not

positioned in quite the same way; it is not friendship that was shared here but a local geography. The death of another with a VAD appeared to have the greatest impact when it was someone whom the individual shared certain characteristics.

Knowledge of the death of others with VAD often precipitated concerns of suffering the same fate.

It's very, very hard. It makes you start analysing yourself. You start analysing what's happened to them, what did they do compared to what you do? You know what I mean, what kind of lifestyle did they have compared to what you do?...But yeah it's hard for you. With some, like I said, are really good friends and when they're alive and that you think you're in the same boat, you've all got the same problem...but it's hard, you just come to one side and think 'ohh it's not me is it'...it hits you hard when you hear about people dying and like I said, then you've got to go and find out why or as much as you can the reason why, was it the way they lived or something they did or was it the machine? (*Ned, 2 years on VAD support*)

Similar effects have been found amongst hospice patients, with nurses reporting that awareness of the death of another patient leads to reflections about one's own future (Rivolta et al. 2014). Ned tried to actively deal with these concerns by seeking out as much information as possible regarding the reason for the individual's demise. Was the death the 'fault' of the individual and some associated lifestyle factor, for which they were in some way culpable, or the result of a problem with the device? A fault with the individual appeared to be the preferred alternative as this affords the VAD recipients some control over their fate; it is something that they can proactively try to avoid. A fault with the device may be more concerning as there is little that they can do to safeguard themselves from this.

For some of the interviewees the more information they could garner about the reason for the death the more power they perceived they had in potentially controlling their own futures. Many appeared to use the misfortunes of others to learn about potential negative outcomes of life with the VAD and hopefully protect themselves.

There was a Swiss bloke, Steve, who had one [VAD] in and I thought he looked fine, but he died with an infection, then to be honest it was a bit panic because I thought 'ahh you can pretty much die on this'. Then there was someone else that died. I think you've got to think everyone's different, it's harsh but you've got to think 'well, right learn from their mistakes, do

your dressings more'...Obviously I wouldn't like want someone to sit there and go 'well these are the amounts that's died, that's why they've died' but I wouldn't mind, like getting told people have died because of this, people have died because of that, instead of saying 'look it'll be fine just do it'. I'd rather get told to the point like 'If you didn't do that, look there's proof that people die of doing it'. And obviously I don't know the full extent of why people have died, but I gather that mostly it's because of lack of doing dressings... it's obviously a shame that someone dies and that but you cannot really let yourself relapse with depression or something because someone else has died. It's just like life, like people die every day you've just got to get on with it. (*Ben, 2 years on VAD support*)

For Ben, the reasons for the demise of others was an important resource in informing his own care regimen. Indeed, the death of 'Swiss bloke, Steve' appeared to be a turning point in Ben's experience, generating a realisation of the reality of his situation. It was not until individuals whom he knew personally had died, that the vulnerability of his situation really dawned on him, bringing forth the realisation that he too could die on the device. The death of others whom one considers similar is likely to bring an awareness of our own mortality into consciousness. Whilst VAD recipients will have experienced a period of time where the threat of death is real and close to hand, following the implantation of the VAD, this threat of death has become more transparent²². However, the death of other VAD recipients may cause this threat of death to enter the consciousness of these individuals. Distancing oneself from others who have died by emphasising differences was one means for dealing with distress. The death of a friend has the potential to derail these individuals, but by seeking out information regarding the cause they are able to keep their own survival at the forefront of their minds. Furthermore, due to confidentiality reasons clinicians are limited in the amount of information they can disclose regarding patient deaths. Indeed, it was unclear in the interviews to what extent the knowledge of the death arose from clinicians or the deceased's family. The impact of patient deaths on other patients has been the focus on previous literature (Rivolta et al. 2014).

²² According to Heidegger, the certainty of death is the fundamental confirmation of our existence in the world, the basic certainty of our being is that we will die (Heidegger, 1985). However, whilst we have an awareness of our mortality at a cognitive level this is not something that we consciously deal with on a day-to-day basis (Little et al. 1998).

Another issue that could arise from the death of a VAD recipient was the feelings of anger and frustration towards the clinical team.

Since I've been coming back in September I'm bumping into more and more people that's having problems with the VADs, you know, like blood clots, infections and blood problems...one of the lads I met on 25, just before Christmas, he was, he seemed alright, he was dead chatty and next minute, it was Saturday his wife arranged to have him a Chinese... she come in and he didn't recognise her and everybody in the room was taken back as if to say 'bloody hell what happened to him?' Five minutes ago he was talking, and then he got shifted out on a night and then he died two days later...I thought 'bloody hell, it can happen that quick', which puts it into perspective...It just seems that a lot of people are now having more problems with it but obviously it's new and it's all to do with infection...since I've been coming back since September and it was glaring, it's pissed me off a bit. (*Stephan, 11 months on VAD support*)

Central to Stephan's account is the dramatic details, the shift from life as usual, of chatting and having a 'Saturday Chinese', to the rapid transition to trouble, where 'everybody in the room was taken back'. Understandably, witnessing such a dramatic shift caused him concerns and brought the fragility of this own mortality into stark relief. Stephan's account suggests a degree of irritation with the clinical team. There is an implication that Stephan did not feel that he had been sufficiently prepared for the likelihood of him experiencing these problems he is witnessing in others living with VADs. Seeing others who are living with the device deteriorate and die provides a potential view of the future that is extremely negative, it is the worst case scenario. Feelings of irritation towards the hospital team may be understandable if individuals feel that they have been unprepared for death on the device as a possibility.

At present, there is little previous literature available regarding responses to death within a patient community, the majority of evidence that does exist has focused on hospice patients. Amongst hospice patients, the death of a fellow patient is often experienced as more comforting than distressing (Honeybun, Johnston and Tookman, 1992, Payne et al. 1996). Under these circumstances, witnessing a 'peaceful death' and the care and attention given by clinicians was experienced as reassuring. Furthermore, death is positioned as a natural part of the journey amongst cancer patients (Ussher et al. 2006). However, those living with VADs are a very different group to hospice patients or those living with terminal cancer, so the transferability of these findings can be called into question. The assumption amongst hospice

patients will be that they are nearing the end of their life; death in the near future is expected. The VAD, on the other hand, is positioned as a short-term bridging device that will sustain an individual until a donor heart is available for them, not as a method of palliative care. Thus, the knowledge of similar others dying with the device is likely to be far more disturbing, leading to upset and concerns over one's own future.

8.6 Conclusion

This chapter has explored the impacts of the VAD on existing social roles and relations and the extent to which social ties develop between those who are living with VADs. Existing social relationships were disrupted by the heart failure illness and the VAD implantation as this prevented them from fulfilment of valued social roles, particularly in parenting and caring for loved ones. Furthermore, relationships with those outside of the immediate family could become strained, due to a perceived lack of support or understanding of what they were going through.

However, social communities that developed amongst those with VADs could be considered to offer the understanding that was often to be lacking from relationships with family and friends. Whilst, not all of the respondents subscribed to this idea of community many found it very beneficial. In addition, there may be a temporal element to this contact. In the period leading up to receiving the device and immediately after implantation, exposure to others who were living successfully with the VAD appeared important for allaying fears and fostering hope of a positive outcome. Furthermore, contact with other VAD recipients enabled comparison to take place that appeared to be a useful tool in allowing individuals to position themselves as fortunate, fostering positive views about their situation. However, negative impacts of these communities were also evident; distress was often experienced following a death within the group. The distress that followed was twofold, grief at the loss of a friend and fear of suffering the same fate. However, this could also be considered to have positive implications as it provides a realistic view of mortality with the VAD and may inspire individuals to manage their condition to the best of their ability and avoid similar outcomes for themselves.

9

‘Being’ a VAD Recipient: A Liminal Experience

Chapter 9. 'Being' a VAD Recipient: A Liminal Experience

9.1 Introduction

In the preceding chapters, I outlined a range of issues that are key to the experience of living with a ventricular assist device (VAD). Whilst these are all important aspects of 'Being' a VAD recipient there is one theme that appears to be core in the experience of these individuals. This theme is liminality, and it forms the central tenet of this thesis. Although the concept of liminality has been introduced in the preceding chapters, it is in this final empirical chapter that complete focus is given to this theme.

This chapter aims to demonstrate how the concept of liminality aids us in understanding what it means to 'Be' a VAD recipient. Liminality has been defined thus:

[Liminal people] slip through the network of classifications that normally locate states and positions in cultural space. Liminal entities are neither here nor there; they are betwixt and between the positions assigned and arrayed by law, custom, convention, and ceremonial (Turner 1969: 95).

The concept of liminality was first developed by the cultural anthropologist Arnold Van Gennep at the beginning of the 20th century in reference to passage rites. A rite of passage involves a change to an individual, in particular to their social status. Turner (1969) highlighted the passage of youngsters into adulthood as the most typical of these rites. The liminal state is marked by ambiguity in one's social state and structure; those who are liminal lie between states. The concept of liminality has previously been applied to the disruption that occurs as part of living with an illness (Frankenberg, 1986; Little et al. 1998). Molzahn, Bruce and Shields (2008) conceptualised the experience of patients with chronic kidney disease in terms of liminality, as they were both independent and dependent, both feeling normal and not-normal. In a review of the usefulness of liminality as a framework for understanding the experiences of cancer survivorship Blows et al. (2012) suggest that liminality provides insights into the ways that survivors may find themselves at the margins of everyday life.

This chapter outlines liminality as a key aspect of living with a VAD; this is due to the uncertainty that is a recurrent feature of temporality for VAD recipients. This section describes how liminality creeps into the experience of 'Being' a VAD recipient at different time points, and the impact that it has on their identity. This chapter begins with a consideration of the VAD itself as a liminal object; this is in terms of the manner in which it is presented to recipients as a treatment option. Secondly, the materiality of the VAD is discussed in relation to how it may give rise to the experience of liminality by restricting the

activities in which the recipient is able to engage. Focus is then turned towards the perception of time, it is suggested that the receipt of the VAD causes attention to be focused away from the future and towards the mundane activities of daily life. Finally, the chapter discusses respondents' thoughts and expectations of the future, and the potential for ending their experiences of liminality.

9.2 The VAD as a liminal object

The VAD itself, as a piece of technology and a treatment regimen, could be considered liminal. From its first introduction by clinicians, the device is presented as a temporary treatment; this is due to commissioning limitations (NHS commissioning board, 2013). This presentation of the device as a temporary solution appears to influence how recipients then orientate towards their life with the device. The VAD is presented as temporary, and as such life attached to it is seen a temporary state. Many of the respondents described how they viewed the VAD as a stopgap until a donor heart could be found, rather than 'the answer' to their condition. Moreover, it appeared that for many of the VAD recipients the device is only acceptable in this temporary role, and the idea of living with the device in the long term was unfavourable. Whilst the VAD could be accepted and endured, this was only until such time as they received a transplant. The VAD itself did not offer a feasible long-term solution to their problem.

Provided it [heart transplant] is going to happen eventually you just keep on day-to-day with just getting on with life...it [the VAD] kept me alive, that's how I feel, it's keeping me alive until such time as I can get the heart transplant. (*Russell, 2 ½ years on VAD support*)

For Russell, the VAD appears unacceptable as a long-term solution to his heart failure. However, having the heart transplant as a potential future in his horizon allowed him to manage his life with the device. The heart transplant was a necessary motivation for enduring the perceived limitations of life with the device. A number of the interviewees shared such a view.

I think while the hopes there of a new heart then you put up with this, you deal with all the nonsense and everything else, if somebody said 'that's all you're going to get' that would be just...I can't even contemplate that. (*Terry partner of Jan, 4 years on VAD support*)

For Jan to spend the rest of her life with the VAD was not only undesirable, or unacceptable, it was beyond comprehension. For VAD recipients, like Russell and Jan, living with the VAD

was always experienced and viewed as a liminal and temporary state; learning to live with the device was not accompanied by a change to their identity whereby they became an established VAD patient, their focus has always been towards the heart transplant. For these recipients the life conferred by the VAD was untenable in the long term. However, given the low rates of heart donation in the UK (MacGowan et al. 2011) the majority of the VAD recipients in this study will never receive a heart transplant. Furthermore, there appears to be a degree of misunderstanding about how the transplant waiting list works, and a lack of understanding that receipt of the VAD changes their status in terms of transplantation. The fact that individuals are living stably on VAD support means they are less likely to receive a transplant as they are not viewed as urgent cases and the presence of the VAD itself complicates the transplant operation. Thus, it may be suggested that presentation of the device as a bridge to transplantation may foster unrealistic expectations about the future. It may prevent 'full' acceptance of the device and the development of a new normality. Previous research has suggested that the acceptability of a treatment may be related to a lack of alternatives (Lehoux, 2004). Indeed, for the interviewees holding on to the hope of a heart transplant in the future may prevent them from fully accepting the VAD, and its limitations, into their lives. Life with the VAD may be looked upon more favourably if it is presented by clinicians as the only, or long-term treatment option, rather than as a temporary measure. Such a presentation may afford the development of more realistic hopes and expectations for the future.

9.3 Receipt of the VAD creates liminal identities

The materiality of the VAD is another aspect of the device that may be considered liminal. In the preceding chapters, specifically Chapters 6 and 7, the materiality of the VAD was discussed in reference to its impact on the undertaking of everyday life. In addition, to the issues discussed previously, the materiality may impact on recipients' lives by enhancing their feelings of liminality. In this instance, the sense of liminality may arise from the restrictions imposed by the physicality of the VAD that impedes the engagement in valued activities. Many respondents described how following the VAD implantation they avoided certain activities due to their perceived incompatibility with the physicality of the device.

Well, I actually went to my first rugby match since I took ill on Sunday, so I'm starting to slowly reintroduce what I used to do. I was a bit nervous at first, but actually it wasn't too bad, 'cos I had my fiancée on one side and my friend on the other, so I was kind of in the middle, so I knew I wouldn't get knocked or anything... it's just the things I want to do. I'm still in the

mind set of 'I'm normal' and I want to go out and do the things that I want to do because, like I say, for my friend's stag party they're going go-karting and paintballing, I can't do those things, and those were the things I would have done in the past. Rather than watch the rugby I used to play rugby, the same with the American football, now days I have to be content with watching it, so it's kind of a whole different thing. (*Jack, 3 years on VAD support*)

Jack's account here could be read as an attempt to try out his old identity, that of rugby player and fan, to see whether this fits with his new body. Jack's concerns about protecting the device prevented him from engaging in activities that he valued such as attending the rugby. As discussed in Chapter 7, concerns about the vulnerability of the VAD, and the weakness it may confer to the recipients themselves, is a major factor in the undertaking of daily life for VAD recipients. Life, for Jack, following the VAD implant involved a total change from his pre-illness life. The VAD caused him to limit the activities in which he participated, resulting in the loss of previously valued hobbies and interests. Such changes may enhance the liminality of the individual's experience unless they are also accompanied by the development of new equally valued activities. Such losses have been suggested to lead to a loss of self (Charmaz, 1983). 'Being' a VAD recipient appears to involve a move away from previous interests. The development and undertaking of new activities that fit with the materiality of the VAD may be seen as the attainment of the new identity of 'established VAD recipient'.

9.4 Time as liminal following VAD implantation

As discussed above, the VAD can precipitate a change in recipients' lives and the activities in which they engage. In addition, it may also disrupt their perception of time, changing its focus. During the interviews, many respondents indicated that they felt they were stuck in some in-between place following the receipt of the VAD.

It's awful, it's an awful feeling you being stuck...at this crossroads you can't go anywhere, it's like you being in a telephone box and not being able to get out. (*Jan, 4 years on VAD support*)

Jan's feelings of being stuck may reflect a sense of boundedness in space and time. This has previously been observed in the experience of cancer patients, where one aspect of the boundedness was the necessary compliance with the medical system and medical regimens (Little et al. 1998). Similarities were evident amongst the interviewees who spoke of the restrictions that the device imposed on their lives. VAD recipients' survival is dependent upon

battery power and medications; Chapter 6 discusses the ways that respondents make sense of this dependency. Another aspect of the boundedness experienced by VAD recipients is the increased dependency upon others for simple day-to-day functions such as washing, which has also been previously observed amongst cancer sufferers (Little et al. 1998). Not only are VAD recipients dependent upon the device to live but also upon others; adapting to life with the VAD involves learning to become dependent upon others in the undertaking of activities of daily life. These feelings of boundedness and being stuck highlight the liminality of the experience, leaving recipients like Jan feeling that they are unable to live their lives to the full whilst living with the device.

Illness in itself can disrupt individuals' sense of time²³. Suffering with illness can break down our ecstatic temporality causing bodily demands to intrude into our consciousness, moving us away from authentic time, which is directed towards the future, and bringing inauthentic time, which is concerned with the bodily clock, to the forefront. In essence, chronic illness disrupts our ability to improvise with time.

My attitude on life changed completely when I got this [VAD] fitted, it's like you take each day as it comes, you get out of bed in the morning you feel well, you get through that day and you see what the next day's going to bring because you never get two days the same. One day can be fantastic and you can spring clean your house or you can walk for miles, you can do anything. The next day you can't get out of your chair. It's swings and roundabouts. (*April, 3 years on VAD support*)

April's perception of time appears to have been altered by the VAD; it is no longer focused towards the future but instead around the practicalities of day-to-day life. Due to the unpredictability of her condition she feels unable to plan her life in advance, but must take each day as it comes. Chronic illness can cause individuals to become preoccupied with treating the disease so that they are no longer heedless of time in its objective flow as

²³ The Heideggerian concept of temporality may be a useful model for understanding the relationship between illness and time perception (Gergel, 2013). Heidegger's concept of ecstatic temporality defines our existence within the world and how directed primarily towards the future whilst being merged with our present and past experiences. This ecstatic temporality is an authentic experience. However, the experience of illness can disrupt this ecstatic temporality, bringing inauthentic time to the forefront. Inauthentic experience is governed by bodily needs. Amongst those with heart failure and with VADs this inauthentic time is focused in the bodily clock and its demands. Illness breaks down ecstatic temporality as the previously unobtrusive world of bodily demands and functions obtrudes into our consciousness (Borrett, 2013).

measured by the clock; instead, they are caught in provisional time looking forward to the next moment of medical work (Morris, 2008). This disruption of time occurs in illnesses where biological imperatives force attention towards the time of the next pill or aspect of the medical regimen that must be adhered to. Living with a VAD may change recipients' orientation to time; as the unpredictability of their condition may make them feel unable to look to the future and the possibilities that it may hold, instead focusing on the day-to-day care required by the device. Similarly, patients undergoing dialysis who are immobile for 4-6 hours per session several times a week work to make the experience bearable and meaningful doing whatever is possible whilst bound to the machine (Ådahl, 2013). Changes to the perception of time may further enhance the experience of liminality. Rather than planning for weeks or months in the future, respondents are focused on their day-to-day functioning. This inability to plan for the future may enhance feelings of boundedness, of being stuck and unable to move on with one's life. Furthermore, this also renders them outsiders as we live in a society oriented towards the future where people are expected to plan.

So, 'Being' a VAD recipient appears to be a liminal existence where attention is focused away from the future and instead towards day-to-day functioning and medical regimens. However, the concept of the 'future' is not necessarily a simple concept for VAD recipients as there are multiple possible futures conceivable for these individuals. The focus of their future could include heart transplantation, explantation, or long-term VAD support. For many recipients the future appeared to be conceptualised as the time 'post-VAD' rather than the immediate future with the device. Many recipients appeared to hold off on fully developing a new life of which the VAD was part, delaying their plans for after they have received a heart transplant. Interviewees described how they delayed activities and life-events for their post-VAD future.

Matt: We're in the process also of buying a VW camper, an old camper and Susie'll say 'it's not the right time, it's not the right time', but when is the right time, you know what I mean?

Susie [Matt's wife]: What we've always said, is after your transplant weren't it but...

Matt: But it could be another couple of years, that. (*Matt, 2 ½ years on VAD support*)

The language of Matt and his wife indicates that they view the heart transplant as something that will definitely happen; although it may take a couple of years, it will happen eventually,

and they have chosen to postpone their plans till this time. However, they do also acknowledge the uncertainty of when this future might be achieved. In reality, not all of those fitted with a VAD will receive a transplant. Indeed, at the end of the fieldwork, five of the twenty participants had received a heart transplant, and as many had died with the device in-situ. Evidently, the heart transplant is not a certain outcome; at best the future of these individuals is uncertain. Although Matt was a stable and established VAD recipient, the future of his focus was the post-VAD future. Whilst Matt had been able to develop an identity as a stable VAD patient to such an extent that he considered the device to be 'part of him', he still did not view the device as an object which would be a stable fixture in his future.

9.5 Liminality as a result of uncertain futures

The uncertainty surrounding their futures plays an important role in the liminality experienced by VAD recipients. Whilst the VAD is intended as a bridge to transplantation, there is no way of predicting when or even if a donor heart might become available. It was evident from many of the respondents' accounts that thoughts of a post-VAD future were a common feature of their consciousness. The majority of respondents were looking towards a heart transplant as they saw this life as having less perceived limitations than the life conferred by the VAD. There was a belief that the heart transplant would afford a greater level of health and physical functioning than was achievable with the VAD.

You see people post-transplant who just seem to be really completely back to where they were...I suspect I would probably be a bit fitter or could get a bit fitter than I seem to be able to do with the VAD. (*James, 11 months on VAD support*)

James' views the VAD as imposing limitations on his fitness levels, preventing him from returning to the level of functioning he had prior to becoming ill. Indeed, whilst the VAD is essentially a prosthetic heart, the current generation of devices work by providing a continuous flow of blood. As such, they do not respond to the added pressure exerted by exercise in the same way that the human heart would do, they are not able to increase their flow depending on the exertion of the individual. Furthermore, many sports and types of physical activities are not feasible due to their incompatibility with the physicality of the device. For many the heart transplant was viewed as their 'answer' to their advanced heart failure, and the future self with a new heart was viewed as a return, or at least a closer approximation, to one's pre-illness self. In addition, whilst respondents focused on the limitations of life with the VAD, there was a tendency for them to neglect, or dismiss, the

limitations carried by heart transplantation. Specifically, little attention was afforded to the potential side effects of immunosuppressant medications. This tendency to neglect the impact of immunosuppressants has been observed in previous studies of VAD patients (Modica et al. 2015).

Interestingly however, there were some respondents who did not desire a heart transplant, who instead expressed a preference to remain on VAD support.

Maybe at the moment even I would prefer it [the VAD] to a heart transplant 'cos those can be obviously risky, can't they, with rejections and things. If I was to get rid of it then that would be great...I wouldn't want to go through that [operation and pain] again unnecessarily. (*Paul, 4 months on VAD support*)

Paul's preference, although hedged, note his use of 'maybe', was to live with the VAD as long as possible before undergoing a heart transplant. He viewed the heart transplant as a risk that he wished to avoid if possible. Although the standard of life conferred by the VAD may not have been ideal, the limitations were perceived as minor irritations which could be endured for the foreseeable future compared to the potentially life threatening risks perceived as accompanying the heart transplant. For Paul, the perceived risks that heart transplantation carried were not outweighed by potential benefits to functioning. Indeed, having a VAD further complicates the heart transplant operation doubling the risk of death during the operation. Thus for Paul, amongst others, it was preferable to maintain the status quo until a heart transplant became an absolute necessity. It appears that for Paul the VAD is the more acceptable choice because he sees it as less uncertain than the potential risks carried by the heart transplant.

Hopes for the future, for another subset of respondents, were focused on neither the device nor the heart transplant, but instead on the possibility of having the device explanted. Explantation is a potential outcome of VAD support as the device can enable a sufficient degree of myocardial recovery for the heart to resume sole functioning. However, this is only a realistic option for a very small number of individuals, generally those who were younger with less damage to their hearts. Ben was one such candidate, he spoke of how removal of the device was something he was actively working towards.

I've got to work...try and get meself fit and that, 'cos I want this out the proper way. I don't want a transplant 'cos obviously you're just on

borrowed time waiting for a transplant and you're on borrowed time when you get one. (*Ben, 2 years on VAD support*)

Ben's reference to explantation as the 'proper way' carries the inference that transplantation is the 'improper' way of having the device removed. Furthermore, his reference to life with the transplant as living on 'borrowed time' demonstrates an awareness that heart failure will be a factor for the rest of his life. Ben voiced his anticipation regarding his life expectancy during the interview. These expectations were based on his father's experiences of heart failure and transplantation. However, Ben does not acknowledge the possibility that advancement in technologies might afford him better outcomes and a longer life expectancy than his father. Progression in medical technologies have enabled us greater ability and potential to treat many medical conditions, including heart failure. Such advancements mean that individuals who may previously have died with their condition, such as those living with VADs, are given a chance at life. Nevertheless, these advancements carry their own uncertainties.

Indeed, as VADs themselves are a relatively new development in the treatment of advanced heart failure, there are some uncertainties surrounding their longevity. These uncertainties were a cause for concern for many of the interlocutors. As the VAD was viewed as having a life expectancy, concerns were expressed about what recourses would be available when this was reached.

Gordon: Well this [VAD] has got a life expectancy, which I think is 3 years then after that you're hitting problems in various shapes and forms sort of thing

HS: Yeah, the possibility of having to have it replaced and things like that

Gordon: Well, yeah I understand that VADs in the States are getting up to six or seven years with them but I don't know if that's the case here.

Gail: But they haven't been used for a great deal of time either so I think it's still all new.

Gordon: I think they've only kind of got people for about 4 years or something here at the moment, so. (*Gordon, 1 1/2 years on VAD support*)

The newness of the VAD caused Gordon and Gail concerns about what their future would hold. They had developed quite specific expectations about how long the device would be able to support Gordon and when he might expect to experience problems. It was unclear from where recipients gained their information regarding the life course of the device,

whether clinicians discussed it with them or it was something that they independently researched or whether it was gained through the sharing of information about experiences within the VAD communities. The uncertainty of the future of these respondents may enhance their feelings of liminality, as there is no real way of them knowing what the future holds for them or when such a future may be achieved.

Furthermore, through the interviews, it became apparent there was a temporality to expectations and hopes for the future, these were not necessarily stable over time. They changed over time spent living with the VAD. Specifically, it appeared that thoughts of the transplant reduced and receded as time living with the VAD increased.

We've been on the pump for so long we'd almost sort of talked ourselves out of it; well, I think we had talked ourselves out of the fact we were going to get the transplant. And the VAD was going to be the way forward forever and ever and ever...we thought we're not going to get a transplant, you know we're living with the VAD, and we'd got our heads around living with the VAD. (*Fred, 3 years on VAD support*)

The longer Fred and his wife were living with the VAD and waiting on the heart transplant list the less likely they perceived their chances of receiving a heart transplant. Moreover, Fred's conception of life with the VAD also appeared to have changed. The VAD appeared to have become a normality for Fred and his partner. Whilst this may have been a different normality, a new normal, than that lived previously; it had nevertheless been accepted at least for the foreseeable future. For Fred and Nancy their focus for the future had moved away from the post-VAD future to a future with the device. The potential of receiving a heart transplant had receded from view. This may have been an attempt to manage their liminality, to achieve a sense of permanence by focusing on the VAD as an enduring feature of their lives, rather than holding out hope for a potentially unobtainable future. However, this normality had once again been disrupted by the development of a potentially life threatening infection, which as a result had resulted in Fred being listed for an urgent transplant. This 'curve ball' disrupted their expectations of what the future would hold. Thus, it appears that it is possible for VAD recipients to develop a new normality with the device, whereby their focus is on life with the device. However, they have no control over the maintenance or durability of this status because their temporality is unstable, as is their body and disease.

VAD recipients horizons of possibility appear to change over time spent living with the device. This is not to say necessarily that the desire for the transplant changes, although this

may be the case for some, but rather the perceived likelihood reduces. The longer one is waiting for a heart the less likely that they see their chances of receiving an organ. Again, this enhances the liminality of VAD recipients; attempts to move on with life and develop a degree of normality around the device are undermined by the unpredictability of the condition. At any moment, the normality that they have achieved may be destroyed and the individual is once again faced with the threat of death.

Although, many respondents were focused on the idea of getting a heart transplant in the future, it is uncertain whether this would offer an end to their experiences of liminality. Indeed, some respondents demonstrated an awareness that a shadow of uncertainty would be present for the rest of their lives.

The only thing I worry about is it [transplant] going to be ok, and how long is it going to last...because when it comes to a transplant it's, I think on average it's about 10-15 years, something like that but it's kind of like how long is a piece of string... my main worry is how long is it going to last? I want to see my nephew grow up, and obviously I want to get married, I want to have maybe have kids of my own, but I kind of think what's held us back from doing that is, I don't want to sort of like have kids and then God forbids something happens kind of thing. (*Jack, 3 years on VAD support*)

Even for those fortunate enough to receive a heart transplant their sense of liminality may persist, as the transplanted organ will not last forever. Transplanted hearts have a limited life expectancy; they will fail or be rejected by the body sooner or later. The uncertainty of his situation held Jack back from important life events like getting married and having children because he was scared of dying and leaving them without a father. Again, this may demonstrate the uncertainty that plays a key role in the experience of these individuals. Such fears about their future may hold them back from pursuing a normal life.

Interviewees differed in their hopes and expectations for the future. Whilst many hoped for a heart transplant, others hoped for an explant, or to live with the VAD as long as possible. A key part of the liminal experience of VAD recipients' was the uncertainty that they faced. This uncertainty was not just about what the future might hold but whether they really had a future at all.

9.5 Conclusion

'Being' a VAD recipient is to live a liminal existence. For the majority of participants, life with the device is experienced as an in-between state, something to be negotiated until the desired outcome of a heart transplant can be achieved. Indeed, this hope for the heart transplant in the future appeared to be a successful motivator in accepting the device in the short term. However, it may also prevent recipients from establishing a new life around the device; they are focused on achieving a post-VAD future and as such neglect the immediate future ahead of them, of which the VAD is part. Although some participants indicated that they were able to develop a new normality around the device, this was an unstable state that could break down without warning following the development of complications. As such liminality remained an underlying presence in the lives of these individuals also.

The manner in which the device is presented as a temporary treatment option by clinicians is likely to play a key role in the development of liminality. The presentation of the device fosters the expectation that the VAD will only be present in their lives and bodies for a limited time. However, as this time stretches on increasingly, without an end in the horizon, recipients may experience feelings of being bound in space and time. VAD recipients themselves have no control regarding if, or even when, they might receive a heart transplant, which is likely to further enhance their sense of liminality.

Receiving a VAD could cause a disruption to the individuals' identity, resulting in a loss of status as well as an inability to engage in previously valued activities. Work is required on the part of the individual to ascertain the extent to which the previous identity can be resumed, if at all. It is also possible over time for the individual to develop a new identity of stable VAD recipient built around the constraints and affordances of the device.

Finally, it was evident that there is not necessarily an end in sight for this liminality.

Although, the respondents expressed hopes and expectations for their futures, an aspect of liminality is likely to be present for the rest of their lives. These individuals will always be living with the lingering shadow of heart failure, waiting for it to recur. It is this pervading sense of liminality that is key to the experience of 'Being' a VAD recipient.

10

Discussion, Recommendation and Conclusions

Chapter 10. Discussion, Recommendations and Conclusions

10.1 Introduction

In this chapter, I bring together findings from my empirical chapters and consider their implications. The opening chapters of this thesis reviewed the available literature, both quantitative and qualitative, exploring the experiences of those living with VADs. This provides a historical background to the development and use of VADs and highlights how these previous studies were lacking in depth of understanding about the everyday realities of living with VADs; they had not fully explored what exactly it means to 'Be' a VAD recipient.

The aim of this study was to understand the essence of what it means to 'Be' a VAD recipient. The objectives of this study were to further the understanding of the day-to-day realities of living with a VAD, to explore the impact of the VAD on recipients' bodies and identities, to explore the extent to which the VAD can be adapted into everyday life and to explore the impact of the VAD on social interactions and communities. In this chapter, I discuss the findings of my study in relation to existing work in this area, outlining the unique contribution of my thesis to the collective understanding of the experience of VAD recipients.

The first section of this chapter presents the findings of the study in relation to their impact for different audiences. I begin with the implications for the VAD recipients themselves. I then outline the implications for health care professionals involved in the care of those with VADs. I also discuss my findings in terms of their meaning for social science studies of VADs. This is followed by a reflection on the research process and a discussion of the future of VADs in the treatment of advanced heart failure. Finally, I discuss potential areas for future research.

10.2 Implications for VAD recipients

This study used interviews to explore the experience of 'Being' a VAD recipient, this approach allowed me to focus on the lived experiences of VAD recipients. I begin this chapter with a discussion of the implications of the study for the VAD recipients themselves.

The central tenet of this thesis is that 'Being' a VAD recipient is a liminal experience. The majority of recipients viewed the VAD with gratitude because it had kept them alive. However, the life afforded through and by the VAD was viewed as a temporary state to be endured until a heart transplant may be achieved. Life is on hold whilst living with the device. This concept is supported by other research which has described the period of VAD support as an 'existential limbo' (Guidry-Grimes and Senderstorm, 2015; Overgaard, Kjeldgaard and Egerod, 2011). Part of this liminality was manifest in participants accounts of feeling stuck in

time whilst living with the device, holding-off on making plans for the future. In a discussion of the ethics of LVAD deactivation, Guidry-Grimes and Sederstrom (2015) suggest that the experience of suffering has the potential to impair the ability to consider possible futures; they illustrate this by drawing on Halpern's (2001) insight:

The problem for people who are suffering is not just that they cannot imagine future goals that are several steps away, but that they also lack enough security and comfort to feel a sense of ongoingness into the immediate future (112).

This is also reminiscent of the liminality that may be experienced by VAD recipients. In the previous chapter, I outline various ways in which liminality comes into play in the experience of persons with VADs.

The sense of liminality experienced by VAD recipients appears to be enhanced by the fact that many recipients do not conceive of the VAD as 'the answer' to their condition. Previous work has found that whilst the VAD is experienced as a relief, the heart transplant is viewed as the cure (Overgaard, Kjeldgaard and Egerod, 2011). In spite of this, the findings of this study suggest that it is possible for some recipients to develop some semblance of a new life with and around the VAD. However, this new life is unstable; it may break down at any moment if the person develops a thrombosis, infection or another complication. This finding concurs with previous studies that have described the 'new normal' achievable by VAD recipients as a 'tightrope walk, a suspension in limbo that tested their faith and confidence in the decision they had made' (Kostick and Blumenthal-Barby, 2015: 1422).

Accepting the VAD and developing a life around the device required the recipient and caregivers to engage in host of management practices. Chapter 6 explored the management of the VAD in day-to-day life, placing particular focus on the impact of the device on the recipients' body. Receipt of the VAD involves the merging of one's body with a piece of technology in an intimate manner. The materiality of the VAD appeared to have far-reaching impacts on recipients' lives. However, in this study respondents indicated that over time it was possible for the device to become an extension of the self. This is in contrast to previous research that suggests complete embodiment of the device is unobtainable, and it is more useful to conceptualise of the device as a prosthetic organ, as the dependence implied by the device prevents it from being forgotten (Modica et al. 2015). The findings of this study indicate that persons with VADs are able to forget about the device, albeit for periods of time. Over time living with the device, it is possible for the device to be incorporated into the recipient's body to such an extent that behaviours that were once disrupted by the device

become automatic once again. I discuss these issues in greater detail in the section on implications for social science.

In chapter 6, I discuss various theories that might help us understand the impact of VAD implantation on the body. I suggest that Oudshoorn's (2015) concept of the hybrid body best explains the merging of self and 'not self' that occurs following the receipt of a VAD. This concept acknowledges the work that is required in order to maintain this body, and the risks that the person incurs if they fail to engage. Failure to engage with the management of the VAD and its external components can have potentially fatal consequences for the person. The work and time required to maintain life with the VAD has been highlighted in previous studies of VADs as DT (Ottenberg et al. 2014). In this project, I found that the responsibility for care taking of the VAD, coupled with the potential side effects, could lead the device to be viewed as a source of frustration. It is important that both clinicians and potential recipients recognise the work that the persons with VADs undertake in order to maintain a stable condition. These responsibilities should be discussed as part of the informed consent procedure prior to implantation, in order to instil in recipients appropriate expectations about life with the device.

The majority of respondents had experienced complications with the device from infections, to thrombosis and strokes. Kostick and Blumenthal-Barby's (2015) have discussed the possibility of narrowing the eligibility criteria for the VAD, excluding those with a high probability of experiencing complications. However, the findings of this study suggest this would be a complex process. Whilst many of the respondents experienced numerous complications with the device, their responses to these differed. Some recipients, like Fred, experienced a great number of serious complications whilst living with the device. However, he was still able to maintain a positive perspective on his life. For others, such as Jan and Darren the experience of complications resulted in a negative outlook on their life with the device. Indeed, for Darren, the complications that he experienced were so distressing that he wished he had never had the device implanted.

The future, for the majority of the respondents, appears to be focused towards achieving a heart transplant. Indeed, as mentioned earlier, many saw the heart transplant as 'the answer' to their condition. Many respondents held the belief that the heart transplant was the gold-standard treatment for advanced heart failure. However, conception of either the heart transplant or the VAD as the answer to heart failure may be problematic as neither treatment actually offers a cure for the condition (Takayama, Thomas, and Naka, 2014). Further, the respondents in this study appeared to have a tendency to close-off thoughts about the impacts

and limitations that would accompany the transplant, choosing to focus instead on the improvements in functioning it would bring. This has also been observed in previous literature (Modica et al. 2015). Organ transplantation as a treatment is not without its downsides: as the transplanted heart is immunologically incompatible, the recipient will have a lifelong dependence upon immunosuppressants to prevent rejection (Rady and Varheijde, 2014). Immunosuppressants carry unpleasant and potentially life threatening side effects of their own, including an increased susceptibility to skin cancer. Furthermore, time spent on VAD support may influence post-transplantation outcomes, persons BTT have been found to have worse outcomes following transplantation than who did not require VAD support. (Ciarka et al. 2015). Additionally, prolonged VAD support significantly reduces survival rates three years post-transplant (Takeda et al. 2015). The majority of respondents in this study demonstrated little to no awareness of these issues. This raises the question whether the expectations of life post-transplant will align with the reality. However, there is also an alternative reading for this neglect of the negative aspects of transplantation. The interviewees may have purposely avoided this information, as they did not want to think about or discuss the negative aspects of what they saw as the 'cure' to their condition. This may be a stratagem for dealing with the protracted uncertainty in their lives. Retaining the possibility of the heart transplant in the future allows an offer of hope and something to work towards.

10.3 Implications for clinical audience

The section above discusses the findings of this study in terms of their implications for the VAD recipients themselves. However, the findings of this thesis are also likely to be of interest to a clinical audience. In this section, I outline some of key findings that have implications for clinicians and make recommendations for care of VAD recipients and the utilisation of VADs as a treatment for advanced heart failure.

Chapter 5 discussed VAD recipients' experiences surrounding the implantation of the device. Many recipients expressed the sense of having no choice regarding the implantation of the VAD. However, I note that respondents do in fact make a choice; they could opt not to have the device. McIlvennan et al. (2014) have utilised 'Dual-Process Theory' to explain the decision making process about VADs for DT. They suggest that some recipients are 'automatic decision makers' who perceive there to be no alternative from the VAD. This was evident amongst the respondents in this study who conceptualised the decision as 'Hobson's choice'. McIlvennan et al. (2015b) emphasise that VADs for DT should be presented as a therapeutic option rather than a necessity, and others have highlighted the importance of informed consent and shared-decision making (Blumenthal-Barby et al. 2015). The clinician

is responsible for engaging the recipient in the decision, this requires moving the person beyond the fear that they either have the VAD or die (ibid.). Further, it has been suggested that a shared decision-making approach should take into account non-intervention as well as intervention (Kostick and Blumenthal-Barby, 2015). Whilst these other studies focus on the use of VADs as DT, shared-decision making is also important for those BTT. Indeed, many of the respondents in this study orientated to their decision as a choice between the VAD or death. They felt they were being offered a ‘Hobson’s’ choice of the VAD or death, and the option of not having the VAD was not presented as a balanced alternative. These findings indicate there may be the potential for further engagement of the recipient in the decision making process. This may involve clinicians placing a greater focus on the realities of the options being presented, and an unpacking of the likelihood of achieving transplantation or explantation, and the presentation of non-intervention as a viable option.

Uncertainty about the future was a major component of the liminality experienced by VAD recipients. However, there was also a temporal element to the VAD recipients’ hopes and expectations for the future. As time living with the device became prolonged, the hope of the transplant faded and the VAD was accepted as the reality for the foreseeable future. In chapter 9, I suggest that recipients’ views of their potential future will be influenced by clinicians’ presentation of the device. For those in this study the device was presented as a BTT, therefore it is not perceived as a long-term solution to their condition. However low heart transplantation rates raise some ethical considerations about this presentation. In the UK, those who are stable on VAD support are not prioritised on the organ transplant waiting list. Of 102 VAD recipients implanted at a UK centre between 2009 and 2013, only 14 were transplanted, and only three of those were within the first 6 months of VAD support (Özalp, et al. 2014). Indeed, at the end of this study, an equal number of participants had died as had received transplants. Those who are stable on VAD support are ineligible for urgent listing on the transplant waiting list so the likelihood of them getting a heart transplant is remote; as such BTT is essentially DT for the majority (Howell and Lim, 2015). Presenting the VAD as BTT may foster unrealistic expectations about the potential for receiving a heart transplant and may inhibit the development of a new life around the VAD. Indeed, other research has indicated that individuals BTT have worse adaptation to the VAD than those with the device for DT (Modica et al. 2015). Furthermore, participants in this study demonstrated confusion and misunderstandings regarding their status on the waiting list. This has been observed in previous studies where many VAD recipients believed they would receive a transplant although they were actually fitted with the device for DT (Blumenthal-Barby et al. 2015).

This indicates the need for better communication and clarity regarding the heart transplant waiting list and the VAD recipients' likelihood for receiving a heart transplant. Furthermore, there may be need to revisit these discussions over the period of VAD support, in particular in response to changes in the individuals status that may affect their likelihood of receiving a transplant.

Further, the low level of heart transplantation, coupled with the findings of this study, suggest a need to re-evaluate the way that VADs are utilised in the UK. Under the current commissioning guidelines, VADs are not offered as a DT (NHS commissioning board, 2013). This is a source of great frustration amongst cardiologists. VADs are commonly used for DT in the US and across the rest of Europe. In addition, the most recent NICE guidelines have recommended the use of VADs as a DT for those ineligible for heart transplantation (NICE, 2015). Westaby (2015) suggests that 1,000 patients a year would benefit from VAD support if the use of these devices were extended. However, he suggests that commissioners perceive the cost of the device as prohibitive and 'palliative care and early death are much cheaper' (ibid.: 48).

MacGowan et al. (2015) have also proposed changes to the transplant listing criteria in order to manage this disparity between the number on VADs as BTT and the number of heart transplants taking place. They suggest that VAD recipients who are ambulatory and at home should be 'registered' at the transplant centre, but not actively placed on the transplant list. This approach has been conceptualised as a form of watchful waiting. Those in this category would be stable on VAD support and thought to have a low risk of serious complications. These changes would lead to a more honest and transparent policy, as there will be a strong intention to transplant those who are actively listed (ibid.). They suggest this would decrease the number of individuals fitted with VADs as BTT freeing up funding and resources that could be directed towards utilising VADs as a DT.

My study has also demonstrated that community plays an important role in the experience of 'Being' a VAD recipient. VAD communities appear to be a useful resource for VAD recipients in learning how to cope with the device. The experiential knowledge shared by VAD recipients offers a level of understanding that is missing from other relationships. Contact with other VAD recipients has been described in previous studies as 'the most valuable information one could receive' (Ottenberg et al. 2014: 372). Further, exposure to others living with a VAD also afforded the opportunity to engage in social comparisons, whereby the person could position how well they were faring with the device compared to others. Other research has indicated that the opportunity to meet other VAD recipients and

caregivers is an important event in the decision making process (see also Blumenthal-Barby et al. 2015; McIlvennan et al. 2015a). Although, there are potentially negative impacts from these communities following the death of another VAD recipient, the positives appear to outweigh the negatives. I suggest that clinicians could further facilitate interaction between VAD recipients as part of the ongoing support system offered following implantation. Currently, the only interaction facilitated by clinicians at the study site was between those considering VAD implantation and stable recipients. This increased interaction could take many forms: a face-to-face support group, email updates and mailing lists or an internet forum. Indeed, a survey study highlights the potential of social media as a platform both for fostering virtual communities amongst VAD patients and disseminating evidence based practices for self-care (Boling et al. 2015).

Chapter 8 discusses the power of the VAD to influence the recipient's identity and how they are orientated to by clinicians. Whereas the person was previously a 'heart failure patient', the device caused them to become something 'other' that was potentially a source of uncertainty for clinicians unfamiliar with the device. There appears to be a lack of knowledge regarding the VADs amongst clinicians working outside of specialist centres. This was a source of uncertainty for the VAD recipient and their caregivers, one that led them to avoid certain hospitals as they were concerned about the level of care they may receive. Furthermore, several respondents provided accounts of being used as a teaching moment for junior clinicians. However, other research suggests this is not necessarily a negative impact that VAD recipients may in fact enjoy teaching others about the device, and that teaching clinicians about the VAD is viewed as a natural consequence of receiving a piece of novel technology (Ottenberg et al. 2014). These findings indicate the need to increase the profile of VADs amongst those working outside of specialist centres. As the number of individuals living with the devices rises, district and community hospitals will increasingly come into contact with individuals on VAD support.

10.4 Implications for social science studies of VAD

The previous sections have discussed some of the findings of the study in terms of their implications for VAD recipients and clinical audiences. I now turn to consider the findings in reference to their implications for social science research about VADs. In the literature review in chapter 2, I introduce the existing qualitative research exploring VADs and outline some of the gaps in understanding. In this section I introduce how the present study has added to our understanding of the phenomenon of 'Being' a VAD recipient.

One of key features of this project that adds to the VAD literature is a specific focus on the experience of 'Being' a VAD recipient. As I outlined in the introduction of the thesis, there is a paucity of literature focused specifically on the experience of living with a VAD. Those studies that have explored the phenomenon have for the most part been exploratory, employing small samples (Casida et al. 2011; Chapman et al. 2007; Hallas, Banner and Wray, 2009; Kostick and Blumenthal-Barby, 2015; Marcuccilli, Casida and Peters, 2013; Overgaard, Kjeldgaard and Egerod, 2011, Zambroski et al. 2009). Larger qualitative studies that have emerged recently have been primarily focused on the decision-making around implantation of the device (Blumenthal-Barby et al. 2015; Bruce et al. 2015; McIlevennan et al. 2014). This thesis explores, in-depth, the experience of 'Being' a VAD recipient using the largest sample of VAD recipients to date. Furthermore, the participants in this study have been theoretically sampled in order to account for as much variation in the experience as possible.

This research project differs from previous VAD studies in the manner in which it orientates to VAD recipients. Although all my respondents were patients at a specialist transplantation centre, my thesis does not focus on the experience of being a patient. The majority of previous studies discussed in chapters 1 and 2 refer to VAD recipients as 'patients' rather than as persons living with a device. This was consciously avoided in this study. The purpose of this study was to look beyond the person as a VAD patient to uncover the wider implications of the device over the entirety of the time they are on VAD support. The experience of what it means to 'Be' a VAD recipient is of interest in this study rather than the 'patienthood' as such. Whilst this may form an element of this phenomenon, it was not an end in itself.

The findings of this study indicate that it is possible for the VAD, and its machinery, to be socially and physically integrated into the lives and bodies of recipients, at least somewhat successfully. This is a process that takes time and work. Medical devices can raise uncertainties about what constitutes and is 'natural' about the human body (Shilling, 2003). Such uncertainty is particularly acute in technologies that collapse the boundaries that have traditionally existed between technology and the body (Bell and Kennedy, 2000). Other VAD research has indicated that the materiality of the VAD can bring about a modification of the recipients self-concept (Marcuccilli, Casida and Peters, 2013). However, they have not examined fully the implications of the merging of the self and 'not-self' that occurs following VAD implantation. Further, Modica et al. (2015) have suggested that a complete embodiment of the device is not possible, they suggested it is better to conceptualise of the VAD as a prosthetic organ. In contrast, the findings of this study indicate that a full embodiment of the device may be possible; however, this is unstable and is liable to breakdown. In chapter 6, I

draw on some STS studies of the body and suggest that Oudshoorn's (2015) concept of the hybrid body offers a useful way of conceptualising the body of a VAD person. The hybrid body accounts for the work that is required to sustain the merging of the self and the 'not-self'. This hybrid body must not be taken for granted.

Further, the merging of self and the 'not-self' that occurs following the VAD implantation can disrupt the manner in which recipients perceive their body. In Merleau-Ponty's (1945) embodied phenomenology, he suggests that the natural state of the body is to be outside of our consciousness; our body is the subject from which we view the world but rarely the object of our perception. The body is our vehicle for seeing (Toombs, 1992). However, pain holds the potential to disrupt this natural state of the body, causing it to 'dys-appear' (Leder, 1990). This study indicates that the implantation of the VAD carries similar effects. VAD recipients must learn to reinhabit their changed body. In chapter 6, I discuss some of the ways in which VAD recipients respond to this change in their bodies and learn to manage the device in everyday life. This develops on previous VAD studies that have alluded to the need of VAD recipients to develop new routines that deal with the restrictions of the device (Hallas et al. 2009; Ottenberg et al. 2014). In this thesis, I provide some concrete examples of the impacts of the VAD on day-to-day behaviours that have been largely missing from previous research.

Furthermore, this thesis adds to previous research by highlighting that the impact of the VAD goes beyond the body; it also changes the VAD person's perception of their environment. Like the changed body, persons with VADs must also learn to reinhabit their environment. The disruption that follows the development of illness has been suggested to transform our ways-of-being in time and place (Irving, 2005). Phenomenologists, including Heidegger and Merleau-Ponty, indicate that an intimate relationship exists between life, habit, and place (López and Sánchez-Criado, 2009). Heidegger suggests that spatiality is inherent to life itself. In phenomenology, the lived body is the locus of our intentions and that physical space is an oriented space (Toombs, 2001). According to Ingold (2000), we are inescapably immersed into our environment; this is a fundamental condition of our existence. However, like our bodies own environment is something that we do necessarily consider.

like our bodies, the houses in which we live are so commonplace, so familiar, so much a part of the way things are, that we often hardly seem to notice them (Carsten and Hugh-Jones, 1995:3-4.)

In a study of the impact of telecare, López and Sánchez-Criado (2009) suggest that the introduction of technology into the home can bring about a specific way of 'being at home'

(351). Part of the work required to maintain the hybrid VAD body is the need to renegotiate familiar spaces. The VAD requires recipients to adjust the choreography of their everyday life to fit around the materiality of the device. Although, previous VAD studies have indicated that practical adaptations may need to be made to the home following VAD implantation (Egerod and Overgaard, 2012), this study is the first that indicates the need for VAD persons to renegotiate the space within their home. Illness can create a new way of being in time and place, making strange the rhythms of habit (Irving, 2005). As with the development of illness, the presence of the VAD can bring the chain of actions that are involved in previously taken for granted activities back to consciousness (ibid.). Using the example of going to the toilet, VAD persons must think about every facet of the behaviour, from picking up the external components of the VAD, to carrying it with them as they walk to the bathroom, and finding a place for it to hang or rest.

Further, Langstrup (2013) suggested that the experience of illness can cause the home to become unruly. The home becomes ambiguous; it is both a place of dwelling and a place in which danger lurks (ibid.). Indeed, the VAD also appears to change the recipient's perception of their environment, revealing unanticipated threats in places previously viewed as safe. As discussed in chapter 6, innocuous household objects such as doorknobs may be brought into consciousness by the presence of the VAD, their nature changed; they now pose a potential threat to safety.

My work also indicates that the VAD has the capacity to influence how places outside the home are viewed. Previous VAD research has highlighted VAD recipients' desire to 'be normal in public' (Marcuccilli, Casida and Peters, 2013: 2461), and I have expanded on this issue in this thesis. In chapter 7, I discuss the potential of the VAD to be a stigmatising object. Visibility is suggested in theories of stigma to play an important role in determining whether something is stigmatising or not (Crocker and Major, 1989; Jones et al. 1984). However, the findings of this study suggest that visibility and discredibility are not dichotomous categories but rather lie on a continuum, on which the VAD appears to fall somewhere in the middle. The VAD alleviates many of the symptoms of heart failure, as such respondents may both look and feel better, allowing their illness to become partially transparent. However, the external components of the VAD are visible and have the potential to be discrediting. This may influence how persons with VADs feel about being seen by others and going out in public with the device. In this thesis, I have discussed in detail how the external components of the device are managed when in public. In particular, I have focused on the practice of disguising the device and discussed the usefulness of sociological concepts of passing

(Garfinkel, 1967) and covering (Goffman, 1963) to explain these behaviours. Furthermore, I suggest that the need to disguise the device appears to lessen as the VAD recipients themselves make sense of the merging of the self and ‘not-self’ and come to terms with the technology as something upon which they are dependent and intimately connected. As such, this project furthers our understanding of the social impact of the VAD, and the mechanisms that VAD persons employ to manage the visual presence of the device.

In this study, I draw on the concept of biographical disruption (Bury, 1982) to explain ‘the VAD recipient’s response to the implantation of the device. Biographical disruption views the development of an illness as a ‘critical situation’ that disrupts the life course. However, much discussion has centred on the universality of this theory as it assumes a shared life trajectory; in reality, there are great disparities in people’s lives. Life events are experienced at different times, and some individuals may endure many traumatic life events whereas others may experience none at all. As such, it has been suggested that biographical disruption is only applicable to lives that have previously been untouched by chronic illness (Reeve et al. 2010). In Heidegger’s phenomenology our experiences are always enslaved by our past, as such responses to the VAD will differ according to the recipients’ historicity. Our histories influence how we respond to chronic illness and ‘critical situations’, as has previously been demonstrated amongst women diagnosed with HIV (Ciambrone, 2001). This thesis demonstrates that whilst the VAD carries the potential to be a disruptive life event, the extent of its impact will depend on previous life experiences. Given the precarious position of the people in this study prior to the implant, where death was a very real a close possibility, the VAD was often experienced as a relief. Furthermore, several respondents had previously endured difficult experiences with other treatments such as ICDs, to which the impact of the VAD compared favourably.

Finally, this study adds to the social science literature exploring the experiences of those of on VAD support by conceptualising the experience of VAD recipients as a liminal existence. I suggest that rather than a transient state, the liminality is extended and likely to be present to some extent for the remainder of their lives. Persons with VADs must attempt to develop a life under this lingering shadow of uncertainty. Like the chronic pain patients in Honkasalo’s (2001) study, the VAD recipients must attempt to find stability in an ‘interstructural state’, a state characterised by chronic ambiguity (340). This study moves our understanding of the experience of VAD recipients beyond previous research as it conceptualises the device as a disruption to the recipients entire existence.

10.5 Reflections on the research project

In this section, I provide some of my reflections on the research project. This includes some of the strengths and limitations of the study. I also discuss the phenomenological approach employed as the methodology for the project and its appropriateness for this study.

The recruitment process for this study involved gaining access to potential participants through clinician gatekeepers. Attempts were made to achieve as wide a range of experiences with the VAD as possible. This involved the use of purposive sampling where individuals with certain characteristics or experiences were sought. However, gatekeepers had ultimate control over who was approached regarding participation. As such, there may be individuals within this population who could have provided interesting insights into the experience of 'Being' a VAD recipient but were not sampled in this study. Such a limitation is somewhat unavoidable when utilising gatekeepers to access a study population. In order to account for this limitation the recruitment strategy could have been extended. Other methods of publicising the study to potential participants could have been employed such as placing posters advertising the study in hospital waiting areas. This would have potentially allowed interested individuals to find out about the study and approach the researcher independently without going through clinical gatekeepers. Future research would benefit from utilising a range of methods to promote recruitment to ensure that a wide range of individuals are sampled.

Another potential limitation is the fact recruitment was from only a single study setting. Although only one site was used to recruit participants, attempts were made to ensure the sample was representative of the wide geographical area covered by the implanting centre. Extending recruitment to another specialist centre was considered during the course of the study, but it was felt that there was sufficient breadth of experiences of living with VADs for the purposes of this study. However, this does impose certain limitations to the findings of the study. It is possible that the experience of living with the VAD differs for individuals based at different hospitals as levels of resources and support may vary. The specialist centre used for recruitment is an established implanting centre which has one of the largest numbers of VAD patients in the UK (NHS Blood and Transplant, 2015b). As such, the experience of individuals under the care of this established team may differ from smaller or newer implanting centres. This is a criticism that can be levelled at much of the existing VAD literature presented in the literature review, which have typically employed a single centre approach to recruitment. Further research can benefit from covering multiple sites.

All the interviews were conducted at the specialist hospital, either within the clinic rooms of the outpatients departments or on hospital wards when the participant was an inpatient. Participants were given the option to choose the location of the interview themselves, and all chose to be interviewed whilst they were attending the hospital. This appeared to be the preference as it reduced the burden of taking part in the interview as these could be timed to coincide with appointments at the VAD clinic. However, there are potential limitations to this using this setting, conducting the interviews on hospital premises may have led some participants to associate myself with part of the clinical team. Although, I made efforts to present myself as a student who was not connected to the university, it was apparent in some interviews that this misconception may have occurred. Furthermore, this may have influenced the participants' accounts of living with the VAD, potentially downplaying problems and negative feelings so as not to appear ungrateful to the hospital and clinicians.

Partners were present in 11 of the 20 interviews conducted. This was an intentional decision when designing the study. It was recognised that utilising dyadic interviews had the potential to curtail participants' responses. However, it was felt that this would be the most appropriate manner of ensuring that respondents felt comfortable in the research process. Furthermore, it was acknowledged that the experience I was seeking, 'Being' a VAD recipient, does not occur in isolation, it is experienced within the context of peoples' lives. Heidegger's phenomenology states that people are not detached; they make sense of their world from within it (Taylor and de Vocht, 2011). The merits of both dyadic interviews and one-on-one have been considered, and it is suggested that there is no preference from Heideggerian philosophy to adopt one over the other (ibid.). As such, although the choice to allow partners to be present in interviews will have influenced the accounts of 'Being' a VAD recipient that were given, I do not believe this is necessarily a limitation of the research. Ideally it would have been useful to interview the VAD recipient and their care giver separately, and then to conduct a combined interview. The separate interviews would afford both parties the opportunity to discuss issues that they may be uncomfortable discussing in front of the other. However, this approach could also impose potential difficulties as the participants were widely geographically dispersed the opportunities to conduct interviews were limited often to the days of the VAD recipients' clinic appointments.

Purposive sampling was utilised during recruitment in order to ensure that as wide range of experiences of living with a VAD were included in the study as possible. Factors considered included the time since VAD implantation, and participants ranged from four months to over four years on VAD support. As such this study provides insight into the different issues faced

by VAD recipients at different time points of living with the device. Throughout the thesis I indicate that the data suggest a temporal aspect of the experience of living with a VAD. However, as each participant was only interviewed once, there are limitations to the inferences that can be made regarding temporality from the data collected. A longitudinal approach where each participant was interviewed at several time points would have allowed the possibility of making greater inferences about how the experience of living with a VAD changes over time. This would have allowed me to explore further some of the issues that have been touched upon in this thesis. For example I have suggest that VAD recipients can come to view the device as part of them after a period of time living on VAD support. Repeat interviews would have allow for the exploration of these issues in greater depth with the potential to highlight key moments in the pathway when views or feelings towards the device changed.

A strength of this study is the iterative approach that was taken to the thematic development; the processes of data collection and analysis ran concurrently throughout the study. Several quality control measures were employed to establish the credibility of the findings. This included peer debriefing and peer scrutiny (Shenton, 2004). Although I did not engage in member checking (Lincoln and Guba, 1985), findings were fed back to members of the clinical team who acted as gatekeepers for the study. They indicated that the themes that emerged from the data fitted with their own experiences of working with the individuals in this group.

This study was underpinned by interpretive phenomenology. The justification for adopting this philosophy as the methodological approach for this study is discussed in detail in chapter 3. The influence of this phenomenological approach is evident throughout this thesis and the findings are discussed in reference to existential themes such as temporality, spatiality, corporeality, and communality (Van Manen, 1984). This study provides new insights, depth and understanding of the experience of 'Being' a VAD recipient. It fulfils Van Manen's (1990) assertion that

A good [phenomenological] description that constitutes the essence of something is construed so that that structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way (39).

I believe that Heidegger's interpretive phenomenology offers a useful lens through which we can uncover hidden aspects of the experience of what it means to 'Be' a VAD recipient. The

purpose of phenomenology is to uncover the essence of a phenomenon and discussion about how this should practically be translated into research. There is some dispute about whether phenomenology should focus on individual or general experience (Finlay, 2009). Indeed, it is evident in this thesis that substantial differences in patients' lives lead to differences in experience. However, this does not necessarily mean that a shared essence of the phenomena does not exist. Halling (2008) highlight that it is possible to accept both the individual and general aspects of an experience, these do not need to be mutually exclusive. Furthermore, Giorgi (2008) advises that interviewing several individuals allows the discernment of individual experience from general experience.

It should also be acknowledged that there are alternative approaches that could have been taken in this thesis. For example rather than focus on the essence of the phenomenon the focus could had been given to the differences between VAD recipients, how differences in their lives such as their gender, life stage or relationship status influenced their experience of living with and managing the device.

10.6 The future of treatment for advanced heart failure

VADs are constantly evolving technologies. Recently there have been major developments in this field; this will influence the experience of living with these devices for recipients.

Firstly, as of July 2015, the first patient was fitted with a MVAD (BBC news, 2015). The MVAD is a fourth generation device; it is a miniaturised and has more settings. It is roughly a third of the size of a HVAD® (HeartWare® 2015d), as demonstrated in Figure 13. The MVAD offers the potential to expand the use of VADs beyond those eligible for transplantation. This will increase the number of individuals living with these devices. However, whilst these are miniaturised versions of the device, they still have external components, which will impart similar impacts on the day-to-day life of the recipient. At present, the device has only been implanted in one individual; an extensive testing phase will be required before it is adopted into routine practice.



CAUTION: Investigational device. Exclusively for clinical investigation.

Investigational device to be used by Qualified Investigators Only.

Figure 13: Size comparison of MVAD® and HVAD® pumps (HeartWare®, 2015d)

Secondly, also in development is transcutaneous energy transfer (TET) technology, which would allow for the VAD system to become fully implantable. This technology would allow for the device to be recharged through the skin using inductive coupling. This innovation has major implications for VAD recipients; it would allow the individual to have periods of time where they were completely independent of the external technology. This holds potential for improvements to recipient QOL (Takayama, Thomas, and Naka, 2014). In addition, this would also drastically reduce negative outcomes for VAD recipients, eliminating the chances of infection (HeartWare®, 2015d). However, as this technology is still in development, and will require lengthy periods of trialling and testing, it is several years away from being adopted into clinical practice.

As discussed previously, MacGowan et al. (2015) have proposed some changes to the heart transplant waiting list, and they advocate a greater role for VADs as a form of long-term support for individuals with advanced heart failure. MacGowan et al. (2015) propose that the UK adopts VADs as a DT, as is current practice in the US and other parts of Europe. NICE (2015) has recently released guidelines to suggest that VADs should be utilised for DT. As such, it appears likely that the use of VADs in the UK will expand in the not too distant future.

10.7 Areas for future research

As this research was for a PhD, it was not possible to explore every aspect of the phenomenon. This final section of the discussion introduces some areas of research surrounding the experience of VAD recipients that I believe would benefit from further attention.

Firstly, the data collected in this study indicate that the impact of the VAD extends beyond the VAD recipient, to partners and caregivers. As discussed in chapter 6, the responsibility for caregiving often falls to the recipient's partner or another close family member this includes activities such as: cleaning the exit wound, sorting medications, keeping track of appointments and battery changes. Several partners and caregivers were involved in the interviews in this study; this afforded me some insight into the impacts of the VAD beyond the recipient. However, I would not want to make too many inferences about the experiences of partners and caregivers from this data alone. The experience of caregivers and partners has received some attention from previous research. It appears the VAD has the potential to precipitate a change partners' identities (Kaan et al. 2010). The caregiver becomes responsible for the VAD recipient, particularly in the event of an emergency (Kitko et al. 2013). Further, the caregiver role may be experienced as a burden; female partners have reported feelings of having little choice but to adopt this role as it is expected by society (Casida, 2005). A key aspect of the caregiving role is putting the needs of the VAD recipient ahead of their own (Egerod and Overgaard, 2012). However, little is really known about the experience of families and partners following implantation and the impacts on quality of life (Bidwell and Lee, 2015). In particular, we do not fully understand the long-term impacts of engaging in this care-giving role. It would be useful to explore whether there is a temporal aspect to partners' experiences, whether the demands upon them are stable over time and whether the caregiver begins to experience frustration at this role. Other researchers have indicated the need for a support system for family members and caregivers (Akbarin and Aarts, 2012; Egerod and Overgaard, 2012). Further attention on the experience of families and partners would allow the identification of potential areas where is this support is required.

Secondly, the majority of VAD recipients included in this study were males. Chapter 7 discusses the potential impact of the VAD on male gender identities and how this is managed. Due to the low numbers of female participants, I have shied away from making too many inferences regarding the specific impact of the VAD on female recipients. However, the findings indicate some impacts particular to female recipients that would benefit from future attention. The VAD could affect the ability to engage in important and valued aspects of

motherhood. Fran expressed her frustration at the difficulties the VAD caused in do day-to-day mothering activities, such as washing her daughters' hair. Furthermore, she expressed distress that her youngest daughter had only ever known her to be unwell. Understanding of the experience of 'Being' a VAD recipient might benefit from a specific focus on female recipients.

As part of the liminality of their experience, I suggest that VAD recipients must learn to live under a shadow of uncertainty, which is present for the remainder of their lives. There is no end to the liminality for these individuals. This assertion could be tested by future research that focuses on those who have achieved a heart transplant or undergone explantation. Many of the respondents in this study outlined their expectations of what life post-VAD would be like, I suggest that there is a tendency to neglect the negative aspects of life post-transplant. A longitudinal study following those supported with VADs until transplantation would demonstrate whether the reality of life post-transplant meets their expectations.

Finally, and most importantly, I believe that the role of palliative care in the treatment of VAD recipients has been neglected by previous research. At present, there is no clarity regarding when the focus of care for individuals BTT moves away from an active focus on achieving transplantation to a palliative pathway. Although VADs are only currently offered as BTT in the UK, the low rates of transplantation mean that for many the transplant will never become a reality, they will die on VAD support. However, little is known about the extent to which VAD recipients are engaged in discussions about end-of-life care and advanced planning. In the US those being fitted with the device for DT receive a palliative care consultation prior to implantation, and this has been in place since 2009 (Mueller et al. 2010). From the respondents in this study it was unclear whether those who were nearing the end of life received any involvement from palliative care or whether the focus remained on the possibility of a transplant right up until end of life. In the case of Albert, who was identified to me by the specialist nurse as being on a palliative trajectory, it was evident that he was aware he was nearing the end of life. However, echoing some of the early work on dying (Glaser and Strauss, 1965), it was unclear whether this had been openly discussed with him by clinicians or whether he had come to this realisation himself.

There will come a time when it may be appropriate to remove the support of the VAD. However, this raises issues concerning deactivation and withdrawal of the VAD as a life sustaining treatment. There is confusion regarding the ethical implications of withdrawing treatments such as VADs, whether this may be akin to euthanasia. Similar issues are currently being discussed in relation to ICDs (England, England and Coggon, 2007). Rady

and Verheijde (2014) suggest that whether deactivation of the VAD is considered physician assisted death depends on whether deactivation of the device leads to the development of a new lethal pathophysiology that is unrelated to the functions replaced by the device.

Boothroyd et al. (2014) on the other hand, do not subscribe to the notion that deactivation of the device could be considered euthanasia as the VAD is preventing the natural progression of an existing disease. It is possible that these ethical issues may result in a reticence amongst physiologists in discussing end-of-life and advanced care planning (Rady and Verheijde, 2014).

The integration of palliation into the care of VAD recipients is an area I believe would benefit from further research. A number of recent studies have made the suggestion that end-of-life planning should be included in the care for those with VADs for DT (Boothroyd et al. 2014; McIlevannan et al. 2015ab), however I suggest this should also be included in the pathway for those fitted with VADs for BTT. The findings for the current study suggest that the focus for individuals BTT remains on achieving a heart transplant even when the individual is rapidly approaching end of life. Procedures should be developed to recognise when the individual is nearing the end of life to facilitate conversations about the individuals' goals and expectations. Further, I believe there is a role of advanced discussions around withdrawal of treatment. When a VAD recipient has experienced major complications or has reached the point where their cumulative morbidities exceed the benefit of the device they may wish to discontinue VAD therapy (Vader and Joseph, 2015). Any further treatment should proceed in line with the person's wishes. Further research should be conducted to identify trigger points and appropriate timing for these discussions.

10.8 Conclusion

In summary, my study adds to previous qualitative literature by focusing on 'Being' a VAD recipient. This research project was conducted at a time when the number of heart transplantations is declining. In this context, VADs may offer the only realistic option for long-term survival for individuals with advanced heart failure. However, relatively little is known about what it means to 'Be' a person living with a VAD. My research has explored this phenomenon in detail, from the first presentation of the device to the potential development of a 'new normality' as a person with a VAD. What is clear from this study is the complexity of this phenomenon.

This thesis has demonstrated the far-reaching impacts of the VAD, which can influence every facet of the recipient's life. The VAD is an intrusion into the recipient's life and body.

Implantation of the VAD creates a hybrid body, which requires a significant degree of work by the recipient, and their partners, to maintain. This study explores this work, and the ways in which the VAD is managed in day-to-day life, in greater detail than previous research.

I have also highlighted the complex relationship between VADs and heart transplantation, and the role this may play in VAD persons' perceptions of the device. The VAD persons in this study, for the most part, did not view the VAD as the 'answer' to their condition, and were hoping for a heart transplant in the future. This is likely influenced by the manner that the device is presented as a BTT. I suggest that there is a need to reconsider the presentation of the device given the low rates of transplantation, and that this may facilitate recipients in developing a life around the VAD.

Finally, the central tenet of my thesis is that 'Being' a VAD recipient is a liminal existence. The life offered by the device is temporary and for many this is a source of great frustration. It is liminal because all the 'new normals' that the recipient may develop are temporal. They are unstable and uncertain and may break down without any warning; the recipient's life is still precarious. Life with a VAD is an extended acute phase. This extended liminality is part of the essence of 'Being' a VAD recipient.

11

References

Chapter 11. References

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12

Appendices

Chapter 12. Appendices

Appendix 1: Glossary of terms

BTT	Bridge to transplantation
CRT	Cardiac resynchronisation therapy
DT	Destination therapy
ICD	Implantable cardioverter defibrillator
ICU	Intensive care unit
MCS	Mechanical circulatory support
NICE	National Institute for Health and Clinical Excellence
QOL	Quality of life
STS	Science and technology studies
TET	Transcutaneous energy transfer
VAD	Ventricular assist device
UK	United Kingdom
US	United States

Appendix 2: Ethical approval letter



Health Research Authority

NRES Committee North East - Newcastle & North Tyneside 1

TEDCO Business Centre
Room 002
Rolling Mill Road
Jarrow
NE32 3DT

Telephone: 0191 428 3564
Facsimile: 0191 428 3432

25 June 2012

Miss Holly Stevens
Institute of Health & Society
Baddiley-Clark Building
Newcastle University
Richardson Road
Newcastle upon Tyne
NE2 4AX

Dear Miss Stevens

Study title: The experience of waiting for a heart transplant for patients with and without ventricular assist devices (VAD): a qualitative exploration.
REC reference: 12/NE/0218
Protocol number: n/a

The Research Ethics Committee reviewed the above application at the meeting held on 12 June 2012. Thank you for attending to discuss the study.

Ethical opinion

In discussion, the Committee noted the following ethical issues.

Members noted that in the answer to A14-1 of the IRAS form the researchers had not involved patients in any stage of the design of the research, but concluded that in this type of research engaging with patients before the research began could taint the research and its outcomes.

It was noted that the researchers would not be using non-English speakers, but reflected that the nuances of language were important for this type of research. The Committee questioned whether a free interpreter service would be available from the local NHS Trust but concluded that this would probably only be for patients and not research.

The Committee noted that there were no independent contacts on the Participant Information Sheet should the participant have any complaints, but felt that as it was a student study using the Academic Supervisor as a contact would be appropriate. Members requested that the Academic Supervisor's contact details were added to the Participant Information Sheet.

The Chair, Mr Chris Turnock, welcomed you and Dr Catherine Exley to the meeting and thanked you for attending.

The Committee commended you on the quality of your application.

A Research Ethics Committee established by the Health Research Authority

Members questioned why the researchers were interviewing patients or carers, and queried whether they should interview both groups.

You replied that the focus of the research was on the patients but conceded that they may not feel up to taking part in the research, and therefore patients can nominate a carer to voice the patient's views on their behalf as opposed to being excluded from the study.

The Committee commented that the carer's story could be different to that of the patient.

You agreed with the Committee's point but replied that interviewing carers about their experience could be a future project.

Members queried whether the findings of the research would be discussed with participants.

You replied that the research team had considered this, and that any initial findings from the original interview could be disseminated to participants at a later interview. Dr Exley clarified that this would be an informal interview and would not include any presentations.

The Committee questioned whether you had considered registering the research on a public database.

You replied that you had not found a suitable database.

Members suggested that you find a suitable public database as an unregistered study may delay any scholarly output.

It was noted that you were due to go on informed consent training in November 2012, but also that the research was due to start in September 2012.

You confirmed that you had undergone GCP training in March 2012 and that the training in November 2012 was for informed consent and ethics.

Decision

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below.

Ethical review of research sites

NHS Sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Conditions of the favourable opinion

The favourable opinion is subject to the following conditions being met prior to the start of the study.

Management permission or approval must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission ("R&D approval") should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements.

Guidance on applying for NHS permission for research is available in the Integrated Research Application System or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

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 approvals from host organisations

Additional conditions specified by the REC

1. Amend the Participant Information Sheet as follows:
 - a) Revise the wording of "The Freeman" to state "the Freeman Hospital"
 - b) Include the contact details of the Academic Supervisor in case of any complaints
 - c) Reword the sentence about inviting participants who have had a heart transplant to state that the researchers would like to "invite you" to a second interview

It is 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).

You should notify the REC in writing once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Confirmation should also be provided to host organisations together with relevant documentation

Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering Letter	Holly Stevens (Newcastle University)	30 April 2012
Evidence of insurance or indemnity	Zurich Municipal Policy Number: NHE008CA03-0013	11 July 2011
Interview Schedules/Topic Guides	Group 1 - Version 1.0	30 April 2012
Interview Schedules/Topic Guides	Group 2&3 - Version 1.0	30 April 2012
Interview Schedules/Topic Guides	Group 4 - Version 1.0	30 April 2012
Interview Schedules/Topic Guides	Follow-up - Version 1.0	30 April 2012
Investigator CV	Holly Stevens	30 April 2012
Investigator CV	Guy A MacGowan	31 January 2012
Investigator CV	T Rapley	
Investigator CV	Catherine Exley	
Letter of invitation to participant	Version 1.0	30 April 2012
Participant Consent Form: Patients - Group 1&2	Version 1.0	12 April 2012
Participant Consent Form: Carers - Group 1&2	Version 1.0	12 April 2012
Participant Consent Form: Patients - Group 3&4	Version 1.0	12 April 2012
Participant Consent Form: Carers - Group 3&4	Version 1.0	12 April 2012

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Participant Information Sheet: Group 1	Version 1.0	12 April 2012
Participant Information Sheet: Group 2	Version 1.0	12 April 2012
Participant Information Sheet: Group 3	Version 1.0	12 April 2012
Participant Information Sheet: Group 4	Version 1.0	12 April 2012
Protocol	Version 1.0	12 April 2012
REC application	IRAS Version 3.4 98946/320830/1/378	03 May 2012

Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

Dr Tom Chadwick declared an interest in this study in that he has previously worked with Dr Catherine Exley and Dr Tim Rapley, however as he had not been involved in this study it was decided that his written comments would be taken into consideration.

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.

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

The NRES website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

Feedback

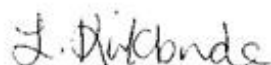
You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the website.

Further information is available at National Research Ethics Service website > After Review

12/NE/0218	Please quote this number on all correspondence
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With the Committee's best wishes for the success of this project

Yours sincerely



A Research Ethics Committee established by the Health Research Authority

Mr Chris Turnock
Chair

Email: laura.kirkbride@sotw.nhs.uk

Enclosures: *List of names and professions of members who were present at the meeting and those who submitted written comments*

"After ethical review – guidance for researchers"

Copy to: *Newcastle upon Tyne Hospitals NHS Foundation Trust*

NRES Committee North East - Newcastle & North Tyneside 1

Attendance at Committee meeting on 12 June 2012

Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>
Professor Alan Boddy	Professor of Cancer Pharmacology	Yes
Dr Mike Bone	Consultant Physician	No
Miss Alexandra Brown	Student	No
Dr Thomas J Chadwick	Clinical Trials Statistician	No
Mrs Alison Chalmers	Engagement Support Coordinator	Yes
Dr Pamela Davies	Principal Lecturer	No
Dr Etta Drews	Senior Lecturer in Psychology	No
Dr Annette Hames	Consultant Clinical Psychologist	Yes
Dr Raj Mohindra	Consultant Cardiologist	Yes
Mr Gary Player	Advanced Practitioner - Cytology	Yes
Mr Christopher Roy-Toole	Lay Member	No
Mrs Anne Scadeng	Lay Member	No
Professor J Mark Thomason	Professor of Prosthetics and Oral Rehabilitation	No
Mr Chris Turnock	Learning & Teaching Advisor	Yes
Dr Simon Woods	Senior Lecturer/Director of Learning	Yes
Professor Matt Wright	Reader	No

Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Miss Sarah Grimshaw	Assistant Committee Coordinator
Ms Gillian Mayer	Committee Coordinator

Written comments received from:

<i>Name</i>	<i>Position</i>
Dr Thomas J Chadwick	Clinical Trials Statistician
Professor J Mark Thomason	Professor of Prosthetics and Oral Rehabilitation

Appendix 3: Participant information sheet



Newcastle
University

The Newcastle upon Tyne Hospitals
NHS Foundation Trust



Participant Information Sheet for semi-structured interviews pre-transplant VAD participants

The experience of waiting for a heart transplant for patients with and without ventricular assist devices (VAD): A qualitative exploration

Holly Standing, Dr Catherine Exley, Dr Tim Rapley, Dr Guy MacGowan

We would like to invite you to take part in our research study. Before you decide we would like you to understand why the research is being done and what it will involve for you. Please read this carefully and ask us if you would like any more information. Talk to others about the study if you wish.

Why have you been chosen and do you have to take part?

We are asking patients who are being bridged to heart transplantation with a VAD to talk about their experiences. It is up to you to decide whether you wish to take part, if you would prefer you can nominate a family member or carer to take part in to the interview on your behalf. You can change your mind about taking part at any time without giving a reason. Whatever you decide it will not affect the care you receive.

What will happen to me if I take part and what will I have to do?

If you are interested in taking part please complete the expression of interest form enclosed and return to the researchers using the pre-paid envelope. We will then contact you at a time to suit you and invite you to take part; you will have an opportunity to ask any questions you may have. If you would prefer, you may nominate a family member or carer to take part on your behalf.

You can choose where you would like the interview to take place; this could be at the Freeman Hospital, Newcastle, at your home or over the telephone. If you decide you would like the interview to take place at the Freeman Hospital, Newcastle we will try to arrange this to coincide with your check up so it is most convenient for you.

The interviews are expected to last around an hour. We will ask you to sign a consent form to take part and for us to audio record the interview. We will be asking you about your experience of waiting for a heart transplant and living with a VAD.

If you receive a heart transplant whilst we are collecting data for the study we would like to invite you to participate in a second interview. There will be an opportunity when we ask you to sign the consent form to state whether you would be willing for us to contact you again to arrange a follow up interview.

Expenses and payments

We will pay all your travel expenses if you provide us with a receipt. Unfortunately childcare costs cannot be funded.

What are the risks and benefits of taking part?

There are no risks of taking part, only the possible inconvenience of giving up your time to be interviewed. You will not directly benefit from taking part in the study, but you will be giving us valuable information to help us understand the experience of living with VADs and waiting for a transplant.

What happens when the research study stops?

We will offer to send you a report of our findings.

What will happen if I don't want to carry on with the study?

You can withdraw from the study at any time, any information you have already provided will still be used with your permission, or you may request for this to be destroyed.

Will my taking part in this study be kept confidential?

Yes, we will follow ethical and legal practice and all information about you will be handled in confidence. Only the research team will have access to the audio recordings which, will be destroyed after the study period. All the information you give us will be anonymised so you cannot be identified. All our records will be kept securely in Newcastle University in accordance with the Data Protection Act 1998. If you tell us anything that suggests you have experienced malpractice or misconduct, or that you are in danger of harm we would ask your permission to report this to someone who could help.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. If you have a concern about any aspect of this study, please contact Dr Catherine Exley (tel: 0191 222 3805, email: catherine.exley@newcastle.ac.uk) who will do her best to answer your questions.

What will happen to the results of the research study?

The results will be used reported in a doctoral thesis and we anticipate the results will be published in a medical journal. You will not be identified in any report or publication.

Who is organising and funding the research and who has reviewed the study?

The study is being funded by and carried out by The Institute of Health & Society, Newcastle University. All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by a NHS Research Ethics Committee.

Thank you for reading this information sheet

Holly Standing- h.c.standing@ncl.ac.uk

