ORIENTATIONS, SPECTRA AND ABSOLUTES:

AN EXPLORATION OF THE ATTITUDES TOWARDS ASSISTED DYING EXPRESSED BY RESPIRATORY AND PALLIATIVE MEDICINE PHYSICIANS, AND THE INFLUENCE OF THEIR SPECIALIST ORGANISATIONS

by

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Abstract

Background: In the UK, public opinion is largely in favour of assisted dying as a legal right for individuals that wish it, but their view is not mirrored by the medical profession. Amongst doctors, there are varying attitudes, but palliative medicine physicians are the most strongly opposed, compared with those from other medical specialties, including respiratory medicine. Such differences might be explained by examining the characteristics of the people entering each specialty, or by the doctors' experiences within the specialty.

Study aims: (1) To explore and understand differences in opinions about good medical care and assisted dying between palliative and respiratory physicians; (2) To understand the influences that determine these opinions; (3) To conceptualise the relationship between professional organisations and their members regarding the above.

Method: This thesis draws on qualitative interview data from specialists in palliative and respiratory medicine, interpreted through thematic analysis. The results are presented in terms of the themes identified through this analysis. In comparing the two specialties, I identified both similarities and differences in their members' attitudes towards both good medical practice and assisted dying.

Findings: I described the similarities between them as *absolutes*, in that all the physicians held the same view on a particular matter. The differences were identified as *orientations,* because most of the members of each specialty tended to hold similar views on a particular topic, which were different from those of the other specialty. At an individual level, the *orientation* would lie on a *spectrum* which exists between the two most polarised views. This analytical framework offers a new approach to the exploration and understanding of professional values and moral practice in medicine, but it has the potential for a wider application in the sociology of the professions.

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Thirdly, with the coronavirus pandemic, I have had the opportunity to return to work in palliative medicine. During the last five months I have been able to put context into the later stages of writing up the thesis by reflecting on my interactions with both patients and other palliative care staff and I thank them all.

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Chapter 1. Introduction

The issues of assisted dying, and particularly whether some form of it should be legalised have been the source of considerable controversy in the UK over the last one hundred years or so (Emanuel, 1994). Despite several attempts to change the legislation in the last 30 years (Brazier, M. and Cave, E., 2016; Laurie, G.T., 2016; Herring, J., 2018), it is still illegal, and this is in part due to the influence of the medical profession. Prominent amongst these doctors have been those from the specialty of palliative medicine (House of Lords, 2005a; Saunders, C., 2006; Association for Palliative Medicine, 2019b). The main stimulus for me to undertake this piece of research was my surprise at the vehemence of the opinions of the members of the Executive Committee of the Association for Palliative Medicine (APM) when they were discussing the subject. I had Joined that committee having been a late entrant into the specialty. I had previously specialised in respiratory medicine, where I had never heard the topic of assisted dying being discussed. So, I decided to explore the values underlying these apparent differences in opinion between members of the two specialties.

As the project developed, it became apparent that there were differences between the specialties in their approach, not only to assisted dying, but also to more fundamental issues, such as the nature of the ‘good’ in medicine. The research question was to explore the nature of these differences in values, and to attempt to interpret the underlying influences that enabled the differences to occur.

In this thesis, I have provided a meaningful account of how the members of two medical specialties developed their values about good medical practice with particular reference to assisted dying, but also how the specialties themselves may have influenced their members. This will be achieved through the analysis of the data obtained from qualitative, in-depth interviews of members of the specialties of palliative and respiratory medicine practising in the North of England in 2018.

The thesis will start with three introductory chapters, in which I will review the relevant background literature. These will be followed by a chapter outlining the underlying methodology, the actual methods and how I analysed the data. These data will then be presented in three chapters, which will be followed by the discussion and finally a summary chapter.

The subject areas of the first three chapters are as follows:

- Medicine as a career, healthcare and the medical encounter, UK medical ethics and ethical frameworks
- The two specialties, respiratory and palliative medicine
- Assisted dying and the surrounding debates

The data were analysed by thematic analysis and from these themes I was able to construct three data chapters in which the concepts that I have proposed in the discussion were developed. I shall finish with a summary chapter, in which I will critically review the research process and reflect on the implications of the findings.

Chapter 2. Setting the Scene

Assisted dying is a very divisive issue in UK society overall, and this extends to the members of the medical profession as well. During my career, I had observed differences in attitudes towards the issue between the two specialties that I had worked in, which were respiratory and palliative medicine. It was this observation, which prompted me to undertake this study. In this thesis, I seek to explore these differences and the moral values that lie beneath them. This is the first of three chapters in which I review the literature that is relevant to the thesis and the underlying concepts that they reveal. In this first chapter, I explore some of the background to current views about good and ethical medical practice. This will then inform the second chapter, which considers the two specialties that I am studying in some detail, and I will explore whether their different origins have influenced their attitudes towards good medicine. In the third, I focus on assisted dying and the position that the two specialties have adopted in relation to the issue.

People choose to become doctors for several reasons, and in the first section of this chapter, I look at these and consider whether there are individual characteristics of the would-be doctor that will be influential in their later career choices. In the second section, the focus is on the doctor and patient relationship and it will become apparent that there are two potential characteristics of this encounter, which are ‘biomedicine’ and ‘holistic medicine’. These will be seen to mark the first of several differences between the two specialties. The section on care and healthcare helps to develop the apparent differences between the two specialties further, by describing how the members of each specialty describe their range of activities.

A key element of the thesis is how the doctors handle ethically challenging situations in clinical practice and their attitudes to morally difficult issues as assisted dying, so the second half of the chapter is concerned with medical ethics and how difficult decisions might be made. I start with a review of the history of medical ethics in the UK and how the subject has developed from the Hippocratic Oath, through doctors’ etiquette to an academic activity taught by ethicists. The sanctity of life is a key concern in medical ethics, and in the next section I trace the concept through the eyes of religious faith, the law and medical practice. I illustrate how, for one side of the assisted dying debate, the principle of the sanctity of life is the central framework in their opposition. In the final section of this chapter, the three other frameworks which are of most relevance to doctors in their ethical deliberations in general, and end of life care in particular will be considered. These are the ‘four principles’, communitarianism and the ethic of care. The relevance of these frameworks in how members of the two specialties develop their values will become evident in the next chapter, when I will be exploring the specialties in some detail. Through these frameworks, further differences between the specialties will also be demonstrated.

2.1 Choice of Medicine

When young people choose to study medicine, there is a presupposition that they have some opinion about the profession of medicine, and also what a career in it entails. In this section, I aim to give some insight into these two aspects. In the first half, I explore the concept of medicine as a profession, a subject which has interested sociologists for nearly seventy years (Parsons, 1951; Hughes, 1963, Freidson, 1989; Nettleton, 2013; Scambler, 2018). It will become apparent that some of its features are exactly those that appeal to potential doctors. On the other hand, other motivators, such as person-centredness, appear to indicate a more humanistic reason for the choice of career. If some members of one of the specialties had expressed particular motivational factors for choosing medicine in the first place, it would suggest that those doctors possessed the features before specialisation.

2.1.1 Introduction: the profession of medicine

Sociologists have taken a keen interest in doctors and the medical profession since Parsons’ analysis of the social roles of the doctor and the patient in society (Parsons, 1951; Woods, 2005). In this context, he proposed a functional relationship between the two, characterised by rights and obligations for both parties. Intrinsic to this relationship was an unequal balance of power between the doctor and the patient, based on knowledge and expertise, as well as society’s attitude towards the medical profession. As well as at a doctor-patient level, the medical profession has held a powerful position in Western society overall for more than 500 years (Hughes, 1963; Freidson, 1989; Stacey, 1992; Brunton, 2019), although this has come under challenge over recent decades. The characteristics of such professional dominance are summarised below (Lupton, 2012; Nettleton, 2013; Annandale, 2014).

- Specialised knowledge achieved through lengthy and expensive training
- Autonomy in relation to all elements of the profession's activities
- Monopoly over practice, dominance over other healthcare providers
- Altruism in relation to the best interests of clients

The point of this description is to identify features that may have been attractive to potential medical applicants when considering their future careers. These include the application of knowledge, autonomy, and power, but also altruism. I shall now review the evidence on why people might choose to enter medicine.

2.1.2 Motives for studying medicine

In this study, I interviewed doctors who had all graduated since the 1980s, so the literature over this period is the most relevant. Three questionnaire-based studies have indicated similar motivational factors for groups of medical students and junior doctors. These included an interest in people, the notion of a 'vocation', a wide range of job opportunities, prestige or status, good salary, being clever at school and the application of natural science. Other conclusions were that women, and those destined for family medicine, were more likely to be interested in people or express a vocational motive (Hyppölä *et al.*, 1998; Vaglum *et al.*, 1999; Heikkilä *et al.*, 2015). Men were more motivated by prestige and salary (Heikkilä *et al.*, 2015), and those who intended to pursue internal medicine were more oriented towards natural science (Vaglum *et al.*, 1999). Another study, using a qualitative methodology (Wouters *et al.*, 2017), attempted to offer a more nuanced view and described 'autonomous motivation' (interest in science or helping people) or 'controlled motivation' (parental pressure or the perceived attractions of the career). The authors concluded that there was a complex interplay of factors, but that the three major motivators were a desire to help people, an interest in science and the prestige of being a member of the profession. Other than the gender differences, these studies did not offer much insight into motivations for studying medicine other than it is a profession which offers a range of motivators including altruism, autonomy, prestige and financial security and the application of science. Perhaps unsurprisingly, these mirror the descriptors of dominant professions that I have summarised in the introduction.

What is particularly relevant to this thesis is whether there were differences in the motivational factors between those who ultimately chose respiratory or palliative medicine, as this could shed light on the two models of medical practice. These specialties will be examined in detail in the next chapter, and this will inform and be informed by the subsequent data chapters. If we return to the students in medical school, one of the first and most important skills for them to learn in clinical practice is the doctor-patient interaction. I will consider this next, as it is also relevant to potential differences between the two specialties.

2.2 The Medical Encounter

What I intend to show in this section is that there are two apparently polarised perspectives of the nature of illness and disease, and that these in turn influence the nature and style of the medical encounter. I describe these positions as biomedicine [1] and holistic medicine, for reasons that will become apparent. To understand the current views on how medicine and society view the doctor-patient relationship, it is appropriate to begin with the history of this encounter from a sociological perspective.

Eliot Freidson, an influential early scholar of the profession of medicine, described the medical encounter in these terms:

> *'The doctor-patient relationship is the primary foundation of all modern healthcare. It is where we start and ultimately where we finish. From its beginnings to the present day, health care has involved interaction between two kinds of people – one who seeks help and a consultant who is believed capable of helping' (Freidson, 1989: 3)*

The encounter between doctor and patient, and especially its dynamics, has been of interest to sociologists for nearly 70 years since Parsons' seminal analysis and interpretation of the relationship (Parsons, 1951). In a subsequent study, exploring how the nature of this encounter had changed over a period of 100 years between 1770 and 1870, Jewson proposed that its dynamics paralleled the theory of medical knowledge of the time (Jewson, 2009). The original publication was in 1976, but his paper was re-published in 2009, with

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[1] The three essential features of biomedicine have been described as:

- Diseases and their causes are purely biological, chemical or physical phenomena
- Emphasis is on research, based on questions that can be studied by randomised clinical trials
- Reductionism: the phenomena are best explained by the properties of their parts
  Valles, S. 'Philosophy of Biomedicine', *Stanford Encyclopaedia of Philosophy*, [Online]. Available at: https://plato.stanford.edu/archives/sum2020/entries/biomedicine/ (Accessed: 23/07/2020).

commentaries from several social scientists working in the field. These articles offered explanations of how concepts of the nature of illness had been interpreted over the preceding 250 years (Armstrong, 2009; Nettleton, 2009; Nicolson, 2009; Prior, 2009). Jewson used Marxist theory to describe 'The mode of production of medical knowledge' (Jewson, 2009: 623). This reflected the sponsorship of medical practice of the time, in other words the source of the doctors' income. Jewson identified three periods of time when the nature of illness was defined in different terms, which he called 'cosmologies' (the essential nature of medical discourse). Bedside Medicine was the first of these, and was practised in the late eighteenth century, when illness was seen in terms of a malfunction of the whole person within her environment, and its interpretation was largely speculative. Because the sponsor of the doctor was the patient herself, her own interpretation of the illness was important in the diagnostic process, and emotional and spiritual concerns were of value in the production of a remedy. In some ways, this reflects the philosophy of holistic medicine (Patel, 1987; Goldstein *et al.*, 1988; Williams, 1998), which will be considered in more detail later. The second cosmology was that of Hospital Medicine, originating in the state sponsored hospitals of Paris around 1800, and lasting 30 or 40 years. During this time, disease processes in individual organs of the body were identified by doctors who also performed post-mortem examinations of their deceased patients. The art of medicine was to make an accurate diagnosis of the underlying pathology in life, which could then be confirmed at post-mortem. This arguably marks the beginning of a biomedical approach to disease, as I will discuss later. The third cosmology was Laboratory Medicine and was an extension of the second, it developed in the middle of the nineteenth century in Germany. The focus had moved from pathological abnormalities within whole bodily organs to the underlying chemical or microbiological processes that were thought to lay beneath the diseased organs. These two cosmologies illustrated the shift from viewing the ill patient as a whole person with health problems, to the patient whose body contains a disease process. Jewson argued that this change marked the beginnings of biomedicine in the nineteenth century. Jewson's thesis may be an over-simplification of the issues, for instance, the importance of the patient's own experience did not completely disappear from the medical interaction during the hospital and laboratory phases. However Jewson did offer a plausible interpretation of the medicalisation of the 'sick man' (Armstrong, 2009). He also provided an explanation for the change in the doctors' approach, which coincided with developments in the understanding of the nature of underlying diseases. Further 'cosmologies' have since been proposed as knowledge and its sponsorship has changed over the last forty to fifty years. Biomedicine now operates at the genetic and molecular level (Prior, 2009), as knowledge is in part driven by the pharmaceutical industry and biotechnology (Nettleton, 2009), and Surveillance Medicine is interpreted as a product of Public Health (Armstrong, 2009). Finally, healthcare information available electronically has enabled patients to gain their own expertise: E-scaped Medicine (Nettleton, 2009). The point is that changes in the perception of the nature of illness have impacted on the conduct of the doctor-patient interaction. Over the last two hundred years or so, the biomedical model of disease has been dominant in the practice of most physicians (Warrell *et al.*, 2010; Ralston *et al.*, 2018; Royal College of Physicians, 2019), and attempts to cure or modify disease processes tend to dominate the consultation. However, as will be seen, the experience of the patient and her interpretations and expectations are also becoming increasingly important. Different specialities within medicine make use of more or less use of these technologies and approaches, depending on what they are seeking to achieve with their patients. With their focus on diseases and treatments, respiratory physicians are primarily inclined towards biomedicine. On the other hand, palliative physicians are interested in people and their suffering, and would be expected to retain an approach more in keeping with 'Bedside Medicine'. (Saunders, 2006; Cherny *et al.*, 2015)

It has been argued that the natural extension of the biomedical model is the emergence of evidence-based medicine (EBM) (Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). This developed out of a perceived need for the provision of proven clinically effective treatments in financially constrained health care systems, in other words healthcare rationing (Scambler, 2008; Nettleton, 2009). The elements of EBM are that the effectiveness of different treatments is measured, and then interpreted using statistics. The quality of the evidence is then graded in a hierarchical way, the best being a meta-analysis of large randomised controlled trials (RCT) of treatments for the same condition (Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). From this process, evidence-based guidelines for the management of the particular condition can be produced and from those, audits of adherence to the guideline are performed. The specialties capable of recruitment to such trials, such as respiratory medicine, have embraced EBM enthusiastically, and it has become a core component of their practice (Woolhouse *et al.*, 2018; British Thoracic Society, 2019). Critics have suggested that that strict adherence to EBM would interfere with the individuality of each doctor-patient relationship and might ignore nuanced patient preferences (Scambler, 2018). Specialties which lack evidence from large RCTs and where the focus is on the individual's experience of her illness, such as occurs in palliative medicine need another approach to good healthcare and I will address this next. (Joint Royal Colleges of Physicians Training Board, 2019a).

During the later stages of the twentieth century, it became evident that a purely science-based biomedicine failed to satisfy all the needs of an increasingly informed public, and several initiatives arose to address these needs. These included patient-centred medicine (PCM), health social movements (HSMs) and holistic medicine. Whilst these contained many shared values, they also addressed the problems from somewhat different perspectives, and it is appropriate to consider each of them.

The development of PCM was largely a move from within the GP community to reset the balance between the doctor and patient, so it was primarily concerned with the conduct of the medical interaction (Balint, 1969; Coulter, 1999; Mead and Bower, 2000; Langberg *et al.*, 2019). In a seminal paper on the conceptual framework of PCM (Mead and Bower, 2000), the following features were identified as being crucial in the encounter:

- Illness to be seen from a biopsychosocial perspective
- Patient-as-person
- Doctor-as-person
- Shared power and responsibility
- Therapeutic alliance

The ideology behind this approach was to re-frame the consultation as one between two equal people who together would identify the problem and develop a mutually acceptable solution to it, to which both were committed. Apart from resetting the power differential in the consultation, the other impact of PCM was to encourage patients to take ownership of their illness and for both parties to acknowledge the potential emotional and social influences on illness (Balint, 1969; Coulter, 1999; Mead and Bower, 2000; Langberg *et al.*, 2019). Patient centred care became an increasingly important political concept from the 1990s onwards (Bury: in Cockerham, 2010), with a number of Department of Health publications stressing the importance of the patient, self-care and the 'expert patient' (Department of Health, 2003; Department of Health, 2004; Department of Health, 2005;

Department of Health, 2008). These sorts of values are also reflected in the guidelines that are provided for medical practitioners by their governing body (General Medical Council, 2013; General Medical Council, 2019a).

The axis of a doctor-patient consultation is dependent on the strength of the commitment of each party to the process. Since Parsons early account of the doctor-patient relationship (Parsons, 1951), a number of other models of the relationship have been described, which are dependent on the locus of power between the participants (Wirtz *et al.*, 2006; Scambler, 2018). A paternalistic relationship is characterised by the (dominant) doctor offering a biomedical interpretation and management plan to a (passive) patient. An interpretive relationship exists when the dominant doctor takes the (passive) patient's values and wishes into consideration as well. There are two other models where the patient asserts her authority. These are termed 'partnership', when the two parties attempt to form a mutually agreed solution, and 'consumerist', when the patient is dominant. Clearly these models represent an over-simplification of what is a very nuanced interaction, and this has been acknowledged (Wirtz *et al.*, 2006).

Health social movements (HSMs) arose out of people's concerns over the dominance of medicine, science, industry and the government in the healthcare debate, without the voices of patients (Brown and Zavestoski, 2004). Therefore, they were more concerned with the wider influences on healthcare and medicine, than with the individual doctor-patient consultation, although it is likely that changes in wider influences would impact on the doctor-patient relationship too.

> *The public can more readily challenge science because it now has a multitude of ways to acquire and share scientific information for personal use and to promote policy change. People obtain extensive knowledge through increased interpersonal sharing of health concerns in self-help and support groups. Information is also obtained through major dissemination of scientific knowledge by the media (primarily print), and by wide access through the Internet to medical databases, research studies and regular news cover-age of the challenges of research in the world of medical science (Brown and Zavestoski, 2004: 683).*

HSMs have been particularly concerned with three aspects of healthcare. These are:

- Availability of, and access to healthcare services
- Disease, illness experience, disability and contested illnesses
- Inequality and inequity in healthcare provision (Brown and Zavestoski, 2004).

In contrast to these structural or larger systemic concerns of HSMs, palliative medicine physicians are concerned at an individual level with their patients' experiences, particularly as they approach death. Palliative medicine's response to suffering at the end of life has been to try to improve the patient's experience during the time leading up to death (Saunders, 1965; Saunders, 1967; Saunders, 2006). Another potential approach would be to shorten this phase actively, which would be assisted dying. In countries such as Belgium, these approaches co-exist (Chambere and Bernheim, 2015; Bernheim and Raus, 2017). Regarding assisted dying, there are two organisations which attempt to fulfil the roles of HSMs, in that they seek to influence national policy on the issue. These are Care not Killing, which campaigns against legislation to allow assisted dying, and Dignity in Dying, which campaigns for it (Care not Killing, 2017; Dignity in Dying, 2017). I will be exploring the debates around assisted dying in some detail in chapter 4.

Holistic medicine (HM) describes an alternative approach to illness to that offered by biomedicine. Rather than focussing on disease processes within the body, the attention is given to the person as a whole in her lived environment and the factors that may influence how she responds to her illness. Some commentators view HM and biomedicine as being completely incompatible with each other in terms of the practitioner's approach (Salmon and Berliner, 1980; Goldstein *et al.*, 1988; Williams, 1998). On the other hand, others offer a more conciliatory view, either that they can be integrated in clinical care (Patel, 1987; Greer and Joseph, 2016), or that they actually exist together on a continuum with the absolutes at the extremities and compromises between them (Frey *et al.*, 2013). These last two studies were both written from a palliative care perspective, which as will be seen, adopts both HM and to a lesser degree biomedicine in its clinical practice. There is also more than one interpretation of what holistic medicine actually includes. For some, the focus is primarily on the nature of the medical interaction, usually described as biopsychosocial (Patel, 1987; Greer and Joseph, 2016).

> *'HM can be defined as an overall approach to health in a framework of dynamic equilibria. This can encompass not only the physical, mental and social aspects of health that are to varying degrees (the latter two to a strictly limited extent) components of the scientific model of health, but also … the realization of self over time and even spiritual dimensions.' (Patel, 1987: 169)*

In this quotation, Patel accepts that biomedicine pays a 'strictly limited' attention to psychological and social factors in illness, but little attention to the person's own identity.

Other authors add another component to their conception of holistic medicine, and they also describe the use of alternative therapeutic 'tools' within their description. These treatments have been described as complementary medicines, and include, amongst others, acupuncture, homeopathy, various types of healing and naturopathy (Aakster, 1986; Williams, 1998). From the biomedical point of view, the main difference between these and their own treatments is the lack of valid evidence to support their use, and this has been a source of dispute between the relevant practitioners (Bird *et al.*, 2013; Nettleton, 2013).

It is apparent that modern healthcare can offer two broad approaches to patient care, the biomedical model, and a more person-centred approach as is described within PCM or HM. It might appear that they conflict with each other, and the question is whether the two approaches can or should coexist in a particular medical encounter. Biomedicine mostly presupposes a knowledge differential between the doctor and the patient, in that in general doctors know more about disease processes than their patients. Without appropriate communication and explanation, this could lead to paternalistic decision making. In other words, the doctor would be making decisions on the patient's behalf, ostensibly for her benefit, but without her full participation. On the other hand, patient-centred medicine requires an openness between both parties, the patient describing her lived experience and expectations, and the doctor listening and exploring realistic solutions with her. Over this and the next chapter, I will show that both respiratory and palliative medicine specialists endeavour to offer care that is grounded in evidence (biomedicine), but which is negotiated in a person-centred fashion.

With this in mind, it is appropriate to examine the concepts of care and healthcare, the latter describing the day-to-day activities of the members of the two specialties.

2.3 Care and Healthcare

In this section, I will illustrate how the key to understanding care and healthcare is to be found in the interpretation of the relationship between the interested parties. Whilst care is largely voluntary and spontaneous, healthcare is contracted and therefore an occupation. In comparing the descriptions of the activities of each specialty, it is possible to illustrate further evidence of the different orientations of each specialty.

2.3.1 Care

There are several ways to consider the nature of care. Firstly, it can describe an act, something that one person does in support of another. Secondly, care describes a relationship between the one-caring and the cared-for, who are ‘reciprocally dependent’ (Noddings, 2003: 58). Thirdly, it can describe the disposition of the individual who cares, some people are naturally more caring than others. An exploration of the history of care for people who were dying gives some insight into the importance of the role of women in the act of caring (Ariès, 1976; Petersen and Waddell, 1998; Kellehear, 2007). Before the nineteenth century, most people died at home from relatively short illnesses, and medicine could offer little to prevent death. The dying person would be nursed by the women of his/her family and immediate community and the event shared between them (Kellehear, 2007). With the move from rural to urban dwelling, management of many dying people, particularly those from the lower social classes, shifted to the poor-law hospitals or homes for the dying (Clark, 2016). Death had become socially less acceptable, and these people tended to be left to the care of the nurses in those institutions. The nurses themselves at that time were mostly sisters in religious orders, acting through a sense of vocation and duty. Gracia described the care ethics that guided them as being ‘more emotional than rational, based in submission, confidence, faith, hope and love, and especially obedience to authority’ (Gracia D, 2002: 93). He described this as the ethic of conviction, a term that had originally been coined by Weber (Gracia D, 2002; Kalberg, 2017). Noddings recognised this tendency but concluded that genuine caring ethics should involve accepting responsibility as well as being open to guidance, if needed (Noddings, 2003). This can be interpreted as representing Weber’s ‘ethic of responsibility’ (Kalberg, 2017 :215). The difference between the two is in the regard for the consequences of the act, rather than just the duty to perform it. Florence Nightingale founded the new ‘professional’ nursing style based on skills and responsibility rather than mere submission, as had existed in the nursing profession previously (Gracia D, 2002). In the division of healthcare labour, it is evident that whilst nurses offer both physical and emotional care, the role of doctors is different in terms of their relationship with their patients. There are also specialty specific differences between how the doctors view their caring role, and this is the subject of the next section.

2.3.2 Healthcare

Freidson described the doctor-patient relationship as the foundation of modern healthcare (Freidson, 1989) and the question that arises is: what does (health) care mean to the members of each the two specialties? One way to explore this is to look at the description of the range of activities of members of each specialty provided by its own members. Such descriptions are to be found on the websites of the major NHS organisations (Joint Royal Colleges of Physicians Training Board, 2019a; Joint Royal Colleges of Physicians Training Board, 2019b; Health Education England, 2020b; Health Education England, 2020a). Not surprisingly, the descriptions tend to reflect the ethos of each specialty. For instance, palliative medicine describes itself in these terms:

> *Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. (Joint Royal Colleges of Physicians Training Board, 2019a)*

The focus for palliative medicine specialists is on holistic care for those suffering from life-limiting illnesses. In a more detailed account of the palliative doctor's daily activities (Health Education England, 2020a), it is evident that a significant proportion of her time is spent providing advice to and liaison with other teams, who have the final clinical responsibility for the patients. 'The tools of the specialty are described as communication, clinical assessment, decision-making and possessing an in depth knowledge of pharmacology. (Health Education England, 2020a). In terms of communication and decision-making, a significant amount of time is spent with the patient and her family, developing a close relationship with them and planning for eventualities that may happen in the future. This involves clarifying care preferences, such as place of care and ceiling of care, and is known as advance care planning (Cherny *et al.*, 2015). The other area in which palliative medicine holds expertise is in 'Clinical analysis of and decision-making in complex scenarios, such as when a patient's clinical needs, preferences and interests are finely balanced and may require skilled application of relevant ethical and legal guidance' (Association for Palliative Medicine, 2019a). This statement from the APM's website describes the specialty's interest in ethical issues, particularly at the end of life. It can thus be seen that the palliative physician's role focusses very much on forming a close relationship with her patients and their families and communicating with them. In this way, they help them make decisions at a difficult time in their lives. Alongside this, the specialty recognises the importance of good symptom control and an in-depth knowledge of the drugs and other interventions used to achieve it.

The descriptions of the range of activities within respiratory medicine give a very different impression of what care means to its doctors. There is a focus on the intimate relationship that the specialty has with acute medicine, and indeed they describe how much of what is known as acute medicine is in fact chest disease (Joint Royal Colleges of Physicians Training Board, 2019b). A second focus is on the multitude of chest diseases that exist and the variety of clinical and technological activities that respiratory physicians undertake within their daily respiratory workload. The overall impression is of an extremely busy doctor, involved with acute medical admissions, outpatient clinics for a variety of chest diseases, performing medical procedures, being involved in the care of patients in the intensive care unit, and of their own inpatients in the respiratory ward (Health Education England, 2020b). The emphasis is on treating diseases and, (hopefully), helping people get better. It seems apparent with such descriptions that the respiratory doctors have less simply less time to be engaged in communication and the relational aspects of the care that was described by those practising palliative medicine. It is also possible that they have less inclination to do so and that that is a factor in the different doctors' choice of specialty.

2.3.3 Summary

Although they share the same word, there are a few clear differences between care and healthcare, as well as some similarities. I have described how relationships are central to both, but that the nature of the relationships is different between the two. The history of care for people who were dying illustrates the key role of women in caring and this will be given a clearer focus in the section on the ethic of care. Good healthcare, as described by each the two specialties, is interpreted differently by each of them. The orientation of palliative medicine is towards forming close relationships with their patients with a view to understanding the nature of their suffering. Their therapeutic approach is underpinned by an approach that acknowledges the physical, psychological, social, and spiritual elements of distress. In contrast, respiratory medicine is dominated by a scientific approach to disease management in which evidence-based practise is central to its therapeutic strategy. The use of medical technologies is central to this approach.

2.4 Medical Ethics in the UK

Although it is widely believed that the Hippocratic Oath is the real basis of ethical Western medical practice (Gillon, 1986; Baker and McCullough, 2008; Herring, 2018), this is really an oversimplification of the issue. Until the middle of the twentieth century, British doctors were largely recruited from among educated gentlemen and they were expected to behave as such and display 'benevolent paternalism' towards their patients in their clinical practice (Brazier and Cave, 2016: 66). In this quotation, Raanan Gillon described an imaginary 'typical medical view' of the teaching of medical ethics that he had experienced during his own medical training:

> *'(In my day) we learnt about medical ethics by learning to become good doctors, in all senses of good. We had had, I hope, good moral education, starting well before we came to medical school, at home, at church, and at school. Our consciences had been formed early on, and when we got to medical school the process continued. We learnt what was done and what was not done, mostly from the example of our teachers ... At the heart of our medical education was an emphasis on character development, on personal integrity, on obeying our consciences - in short, on being a good chap. We never heard about utilitarianism and deontological theories of ethics or even about the virtues; we just learned what was appropriate in which circumstances' (Gillon, 1986: 29).*

What he described here was the idea of the wise paternalistic physician passing on his virtues and skills to the next generation of like-minded doctors as if by an apprenticeship. Indeed, the first duty of a physician, as set out in the Hippocratic Oath, was to pass on his skills to the next generation of doctors, 'to teach them this art if they so desire' (Miola, 2007: 21). It is important to note that the profession of medicine had already secured a monopolistic control over its own activities by this time (Stacey, 1992; Porter, 2006; Nettleton, 2013; Scambler, 2018), so they were able to set their own standards and maintain them without external influence.

Gillon was writing a few years before the GMC declared that medical ethics should become a core component of the medical curriculum (General Medical Council, 1993; Doyal and Gillon, 1998). Five years after the GMC decision, the core curriculum was published in a consensus statement by all of the recognised teachers of medical ethics in the UK at that time, one of whom was Gillon himself (Ashcroft *et al.*, 1998). In fact, although medical ethics did not become a mandatory part of undergraduate medical training until the 1990s, ethical discourse in medicine was evident during the preceding decades. For example, a voluntary initiative had started in London in 1963, the London Medical Group (LMG) (Stirrat, 2015). This was a group, initiated by Rev Edward Shotter, where medical students and junior doctors could explore the wider aspects of medical practice. Shotter had joined the Student Christian Movement in 1963 and it was through this organisation that he had developed the LMG (Boyd, 2019). One of their earliest guest speakers was Dr Cicely Saunders, who was at the time working at St Joseph's Hospice and developing her own ideas on hospice and end of life care, as well as the ethics of such care. In 1972 the Society for the Study of Medical Ethics (SSME) was established by (then qualified) LMG members, and the SSME subsequently evolved to become the Institute of Medical Ethics. It also went on to publish the Journal of Medical Ethics (Stirrat, 2015; Institute of Medical Ethics, 2020). Reverend Shotter's involvement with the LMG illustrates another change that was occurring at the time, namely that professionals other than doctors were becoming involved in medical ethics. It also became evident around this time that tensions were developing between the medical professionals and those from the humanities regarding the ownership of medical ethics. For instance whether learning from the virtuous practice of the experienced physician should be replaced by academics teaching ethics as a branch of philosophy to medical students (Pellegrino, 1989). Despite such concerns, it is apparent that medical ethics had moved on from being merely medical etiquette to a discipline taught by trained ethicists but practised by doctors.

In this thesis, I am exploring doctors' ethical values with reference to good care, and in particular, the morality of assisted dying. The assisted dying debate revolves around the question of whether a person should have the right to be able to choose to die when they want, either at their own hand (with the assistance of a doctor to provide the drugs), or by the doctor's hand (active voluntary euthanasia). Underlying this, is the question of whether human life has a special value over and above the value the person living it attributes to it. This has been described as the sanctity of life. In the next paragraphs, I will explore the concept of the sanctity of life from several perspectives.

2.5 Sanctity of Life

The view that human life is a *basic, intrinsic good* (Keown, 2012: 5), can be traced back through its religious, medical, philosophical and legal origins over more than three thousand years (Wicks, 2010; Baranzke, 2012; Keown, 2012). It is said that the actual phrase 'sanctity of life' was coined in 1951 by a Presbyterian preacher, when he was discussing euthanasia and the Christian attitude of valuing people and their lives (Baranzke, 2012). In legal and philosophical discourse, another term, the 'inviolability of life' is also used to express the unique value attributed to the lives of human beings (Dworkin, 1994; Keown, 1995; Keown, 2012). For the purposes of this thesis, I shall use the former term in my review of the subject throughout, despite its religious connotations.

Probably the earliest recorded references to this issue are in the Old Testament of the Bible, and therefore represent the Judaeo-Christian tradition of faith. Wicks wrote: 'The most well-known assertion of the sanctity of human life in both the Christian Bible and the Jewish Torah is to be found in the Ten Commandments, the sixth of which commands 'thou shalt not kill'.' (Wicks, 2010: 24). Underlying this attitude towards the prohibition of killing other people is not just the sanctity of their individual lives, but that 'the killing of human life is an assault on God in whose image mankind is made' (Novak, 2007: 36). This quotation, from a Jewish perspective, mirrors the commonly held Christian view that as life is a gift from God, it is not man's to take away. For instance, words to this effect were quoted by Pope John Paul II in his 1995 encyclical (Wicks, 2010).

Historically, Western medicine has also supported the sanctity of life, although not necessarily from a Christian perspective. The Hippocratic Oath is largely viewed as being the origin of Western medical ethics and was probably produced by the Hippocratic Corpus around 500 BCE as a code of practice for the doctors of that tradition (Gillon, 1986; Baker and McCullough, 2008; Emanuel *et al.*, 2016; Herring, 2018). In taking this oath, amongst other declarations, the doctors pledged not to provide the means (poison) to take a life, and this has been interpreted as a prohibition of doctors' involvement in assisted suicide. Today this section of the oath is understood to mean that doctors should not kill their patients intentionally (Emanuel, 1994; Brazier and Cave, 2016; Laurie, 2016). This absolute respect for human life largely persists in Western medicine, although it must be noted that there are an increasing number of countries or states in which some form of assisted dying has now been legitimised (Emanuel *et al.*, 2016; Bernheim and Raus, 2017; Saad, 2017). A systematic review of doctors' views on assisted dying services, in jurisdictions in which it had been legitimised, described a range of attitudes amongst the relevant physicians. The doctors' views on the issue varied from support and cooperation with those services, through ambivalence about it, to opposition and conflict with those trying to provide the service (Gerson *et al.*, 2020).

In both UK law and medicine, the sanctity of life is absolute in terms of the intention of the doctor towards her patient. The House of Lords Select Committee on Medical Ethics (1994) was constituted to consider the issue of 'assisted dying for the terminally ill' amongst others. The decision of the committee was based on the evidence that had been presented to it and discussed by its members. Lord Walton, the chair and a doctor himself, summarised their opinion in the following terms: 'Ultimately, however, we concluded that such arguments are not sufficient reason to weaken society's prohibition of intentional killing, which is the cornerstone of law and of social relationships' (House of Lords, 1994). Eleven years later, John Finnis, the philosopher and lawyer, made the following statement to the House of Lords Select Committee on Assisted Dying (2005).

> *At present there is a clear principle: never intend to kill the patient … That is the Law, it is the long-established common morality, it is the ethic of the health care professions … there is a bright line … it rests on a rational principle that a person's life is the very reality of the person, and whatever your feelings of compassion you cannot intentionally try precisely to eliminate the person's reality and existence without disrespect to the person and their basic equality of worth to others (House of Lords, 2005b: 553).*

These and other legal rulings have confirmed that the sanctity of human life is a key principle within the British legal system. It must be respected by the medical profession, in their therapeutic intentions towards their patients (Keown, 1995; Brazier and Cave, 2016; Herring, 2018). This will be considered in more detail in Chapter 4.

2.6 Ethical Frameworks

When a doctor is faced with any clinical situation, there is always more than one option of what she can do. For instance, how does she decide whether to offer cardiopulmonary resuscitation to a 90-year-old patient who has suffered a severe stroke? She could approach the decision-making process in several ways, and I call these the ethical frameworks. I have already described the sanctity of life, which can be seen from a legal or religious perspective, as a prohibition of intentionally killing a patient. There are however a number of other viewpoints, which doctors draw upon to guide their decision-making, and these are the subject of the next section.

2.6.1 Ethical principles

In 1978 Beauchamp and Childress published the first edition of their textbook on medical ethics, It is now in its eighth edition (Beauchamp and Childress, 2019). As philosophers, their aim was to provide 'a systematic analysis of the moral principles that should apply to biomedicine' (Beauchamp and Childress, 1983: ix), from their analysis of moral and ethical theory, they defined four relevant principles. This 'four principles' approach has been strongly supported by the UK medical ethical establishment over more than forty years (Gillon, 1994; Gillon, 2015), and continues to be the framework most widely taught to medical students. The four 'prima facie' principles of ethical practice described are beneficence, non-maleficence, autonomy, and justice. Prima facie implies that the principle is binding unless it conflicts with another one (Gillon, 1994), and herein lies one of the criticisms of this approach, which is: which principle should take preference when there is conflict between them? The first two of these four principles reflect parts of the Hippocratic Oath (to act for the benefit of the patient and not to cause harm) and have guided the paternalistic physician for many years. However, autonomy has become the dominant principle over recent years in the UK and USA, both in medical practice and medical law (Brazier and Cave, 2016). The Montgomery case [2] involved a pregnant woman and her choices around childbirth. The court took a strictly patient centred approach towards her entitlement to make an informed decision about the treatments offered even if it was different from that proposed by the healthcare professionals. In the judgement the importance of patient autonomy and informed consent were highlighted. This prioritisation of autonomy reflects society's move towards liberal egalitarianism over the last 50 years or so (Kymlicka, 2002; Rawls, 2005; Gaus *et al.*, 2018; Forrester, 2019). In the context of the euthanasia debate, the beneficent physician who values life above all else may be at odds with a suffering patient who wants her life to be ended. Currently in the UK, the law would support the doctor's non-maleficent attitude over the patient's autonomous wishes, in the

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[2] Montgomery v Lanarkshire Health Board [2015] UKSC11

example just described. Professional philosophers and other academics have also expressed theoretical objections to the use of these four principles as a basis for decision making in ethically contentious circumstances (Clouser and Gert, 1990; Cookson, 2015; Dawson, 2015; Prah Ruger, 2015; Rhodes, 2015). However, the problem with applying a purely academic approach to a life and death situation is that individual and relational values do not fit into rigid, logical moral rules. For this reason, the four ‘principles’ describe areas that doctors do sometimes consider to be relevant in a pragmatic way during ethical deliberation at an individual clinical level, although clinicians have also criticised the approach as reducing ethical deliberation to a ‘tick box exercise’ (Kong, 2015).

2.6.2 Autonomy

Although the term ’autonomy’, meaning ‘self-governing’, dates back to ancient Greek politics (Woods, 2005), my concern in this thesis was with the interpretations of the concept that were expressed by the research participants, and indirectly by their patients, as they described in their interviews. From this point of view, the following quotation suggests that modern ideas about autonomy date back over the last 100 years or so.

> *In the western tradition, the view that individual autonomy is a basic moral and political value is very much a modern development. Putting moral weight on an individual's ability to govern herself, independent of her place in a metaphysical order or her role in social structures and political institutions is very much the product of the modernist humanism of which much contemporary moral and political philosophy is an offshoot. (Christman, 2018: 2)*

Before considering the ‘modern’ interpretations, it is worth thinking about the earlier notion of ‘moral autonomy’, as described by Kant, who described the competent individual voluntarily choosing to do what is morally right, because it is right, rather than because that is what she wants or desires to do (Woods, 2007; Christman, 2018). Although it might appear to have little relevance to current ideas about patient choice, I shall attempt to show later in the thesis how offers to ‘do what’s right’ may have a part to play in the euthanasia debate.

As I have indicated, autonomy, in the form of patient choice, has become the dominant ethical value in Western medicine. However, within this, there are several more formal interpretations of what autonomy should mean, but they all have limitations, as proponents of the different versions point out (Etzioni, 1998; Sandel, 1998; Mackenzie and Stoljar, 2000).

Modern interpretations of autonomy range, to some extent, in the degree to which others with an interest in the proposed course of action might be affected by that action and should therefore be involved in the decision. For example the expression of libertarian autonomy would be solely driven by that individual's desires, without any consideration of the consequences of the action on other people (Maclean, 2013). Liberal autonomy implies that are all individuals have with an equal right to be free from external interference in expressing their will. However, the obligation implied in this approach is that they should not interfere with other peoples' freedom either (Mill, 2003; Christman, 2004; Woods, 2005; Mandle, 2009; Maclean, 2013). Liberal autonomy has become popular over the last fifty years in Western society in general, influenced by egalitarian ideas of justice (Rawls, 1973; Kymlicka, 2002; Rawls, 2005; Wolterstorff, 2012; Forrester, 2019). This view, as will be seen later, largely underpins pro-assisted dying arguments (Brazier and Cave, 2016; Herring, 2018). An individual's decisions and actions will, however, have an impact on those in her immediate environment and the wider community as a whole. It is the consideration of these that underlie the notions of communitarian and relational autonomy (Sandel, 1998; Mackenzie and Stoljar, 2000; Downie and Llewellyn, 2012), which are outlined below. Although described as interpretations of autonomy, both communitarianism and the ethic of care, which is closely related to relational autonomy, also describe ethical frameworks in their own right, so I will consider each separately.

2.6.3 Communitarianism

I shall consider communitarianism from two perspectives. These are firstly, communitarian ethics as a philosophical discipline (Bell, 2016), and secondly the notion of a communitarian society as a concept of political philosophy. The thrust of the communitarian philosophical view is that as members of a society, people are embedded in its social organisation, and they are bound by its traditions. These include loyalty, mutual support between fellow members, a respect for the family structure and respect for religious faith. Charles Taylor, one of the proponents of this philosophy wrote that: 'Man is a social animal, indeed a political animal, because he is not self-sufficient alone' (Taylor, 1985: 190). It is apparent that this attitude lies in conflict with the liberal view of an individual's ownership of her rights and actions, as long as they do not interfere with anyone else's (Simhony and Weinstein, 2001; Wringe, 2006).

Although communitarianism, as described above, is not necessarily linked with religious faith, there had also been references to a similar philosophy in the Judeo-Christian literature. What are now considered to be communitarian values had for instance, already been described in the Bible, and embraced in Catholic theology. For example, the Christian community was described in the Acts of the Apostles in the following terms: ‘the whole group of those who believed were of one heart and soul’ (Harvey, 2004: 401). Of particular relevance to this study is the traditional Christian communitarian approach towards their fellow human beings. Everyone should be respected as a member of her community, the importance of her family is acknowledged and there is duty amongst the members of the community to nurture that individual in whatever her needs are. For example, from a Catholic communitarian perspective, Eberl both condemned assisted dying, and proposed society’s obligation to provide relief of suffering for those who are dying. His argument was that within a community, other people have a legitimate interest in a dying person’s welfare, and are duty bound to help her in her suffering. He described the mutual obligations in the following terms.

> *‘A two-fold set of responsibilities (a) on the part of the suffering dying person not to assert their autonomy – understood in an individualistic, libertarian sense – by removing themselves from their community and (b) on the part of the communities to provide the genuinely compassionate presence of caregivers, and social support of such caregivers, to suffer with the terminally ill so that they may potentially realize various benefits – for themselves, their caregivers and the wider community – in confronting their physical and existential suffering.’ (Eberl, 2018: 49).*

Christianity was not the only faith to embrace communitarian values however, as the Jewish philosophers Buber and Levinas demonstrated (Zank and Braiterman, 2014; Bergo, 2019). Both were concerned with the reciprocity of the relationship between two people and the mutual responsibility that it entailed (Wodehouse, 1945). Using their philosophical framework, commentators have explored the two-way relationships that exist between healthcare professionals and their patients and their interdependency (Westerhof *et al.*, 2014; Burns, 2017). I will consider this reciprocity in the caring relationship in more detail later. The relevance of the communitarian approach at a personal level will also become evident in the data, in relation to attitudes about the need to protect the vulnerable in society, who in this context are people who are dying.

The term ‘communitarianism’ was first used in a political context by John Goodwin Barmby, the founder of the Universal Communitarian Association and a prominent Chartist, in 1841

(Etzioni, 2018). After this it did not appear until the 1980s, when communitarianism arose as a counter-argument to Rawls' concept of justice, which was based on an individual's rights over those of society (Rawls, 1973; Forrester, 2019). Rawls' idea of liberal egalitarianism had been adopted by many political philosophers in the USA and UK over the following years, and was also embraced by UK politics and society in the latter decades of the twentieth century. However, the proponents of communitarianism challenged the belief that individuals could make choices independently of society, because people are social animals and their sense of self is a social product (Selznick, 1987; Etzioni, 1998; Bell, 2016). There appeared to be an absolute polarity between Rawls' ideas of the inviolable rights of individuals and the communitarian view of the self as a social product, and the interdependency that that implies. In an attempt to address this, compromise positions were subsequently proposed, such as welfare liberalism (Rawls, 1973; Selznick, 1987) and responsive communitarianism (Etzioni, 1998), which appeared to try to bridge the philosophical gap between the extremes and acknowledge a balance between liberty and social order (Etzioni, 1998). In his analysis of political theory and principles, Kymlicka compared and contrasted the development of the values of liberal and communitarian societies in the following way:

> *'In a liberal society, the common good is the result of a process combining preferences, all of which are counted equally (if consistent with the principles of justice). All preferences have equal weight not because they have been judged by the state as having equal intrinsic value, but because 'they are not evaluated at all from a (public) standpoint' (Rawls 1982: 172). As we have seen, this anti-perfectionist insistence on state neutrality reflects the belief that people's interest in leading a good life is not advanced when society discriminates against the projects that they believe are most valuable to them. Hence the common good in a liberal society is adjusted to fit the pattern of preferences and conceptions of the good held by individuals.*
>
> *In a communitarian society, however, the common good is conceived of as a substantive conception of the good life which defines the community's 'way of life'. This common good, rather than adjusting itself to the pattern of people's preferences, provides a standard by which those preferences are evaluated … A communitarian state can and should encourage people to adopt conceptions of the good that conform to the community's way of life, while discouraging conceptions of the good that conflict with it.' (Kymlicka, 2002: 220)*

The point that Kymlicka was making is that communitarian societies express the core values (of the nature of good) that they expect their members to adopt, whilst liberal societies would remain neutral and defer to individuals to make their own choices about the nature of the ‘good’. The relevance of this exploration of liberal egalitarian and communitarian societies will become apparent later in the thesis, when I will be considering the organisational structures that govern the specialties of respiratory and palliative medicine.

I have described how a communitarian framework may be relevant in this thesis from two points of view. Firstly, a communitarian organisation, in defining the nature of ‘the good’ for its members, sets out the standards of behaviour that it expects them to adopt. This is in contrast to the liberal society, which encourages its members to form their own values without external influence, in other words the state remains neutral (Kymlicka, 2002; Etzioni, 2018). In practice, compromises between these two apparently opposing viewpoints must be found: ‘Autonomy and the common good are two such core values that need to be balanced’ (Etzioni, 2018: 9). In the next two chapters, I will be exploring the history and development of the Royal College of Physicians (RCP), the British Thoracic Society (BTS) and the Association for Palliative Medicine (APM), with these considerations in mind. Secondly, the contrasting liberal and communitarian philosophical approaches at a person-to-person level will also be explored in relation to the doctor-patient interaction in these specialities. This will be shown to have particular relevance to end of life issues and debates about assisted dying.

2.6.4 Ethic of care

Another approach to morality with some similarities to communitarianism is the ethic of care. Both stand in clear contrast to the ethical frameworks that rely on moral principles such as justice or deontology to define the morality of an act. The notion of an ethic of care arose from the work of Carol Gilligan into the development of human values (Walker, 1984; Muuss, 1988; Gilligan, 1993). She was reacting to earlier studies by Lawrence Kohlberg, in which he suggested that males possessed greater moral maturity than females (Kohlberg and Kramer, 1969). Kohlberg’s (male) morality of justice described the importance of abstract moral principles, individual autonomy and rights, fairness and the importance of rules, in other words exactly those values that defined the ‘principles’ approach (Kohlberg and Kramer, 1969; Brabeck, 1983). On the other hand, women expressed a different morality of care and responsibility. This was characterised by the importance of personal relationships, caring for each other, non-violence towards others and of taking responsibility for themselves and others (Brabeck, 1983; Gilligan, 1993). Gilligan’s studies were criticised on methodological grounds and also that they implied a binary distribution between the genders, namely that all men expressed a morality of justice, and all women one of care (Brabeck, 1983). However, within feminist bioethics, there were concerns about making generalisations that linked women with a preference for care. Some feminist ethicists were critical of the ethic of care on the grounds that they were ‘shaped in the contexts of oppression that may permit “moral damage” to women’s agency’ (Norlock, 2019: 19). In a male dominated society there has been a gendered distribution of labour that has traditionally placed women in caring roles and this has become the expected norm for them, hence their preference for it (Noddings, 2003). In providing a feminist critique of communitarianism, Eva Feder Kittay exposed the differences between the proponents of the two frameworks (Kittay, 2001). Whilst they both valued the community because of the interpersonal relationships that exist within it, feminists were uncomfortable with some of the traditional structures within communities. For instance, the conventional role of the woman as a wife and a mother would restrict women’s opportunities to take on any other roles in society, and similarly society expected women to take on the caring role for frail and vulnerable family members. Relational autonomy requires us to accept that we are all socially embedded and cannot act entirely independently of others but need to consider the needs of those with whom we have relationships, but not necessarily on gendered lines (Mackenzie and Stoljar, 2000; Kittay, 2001; Downie and Llewellyn, 2012).

In their support of their theory, care ethicists have stated that as care is necessary for human survival, it is more basic to morality than duties or rights, which are abstract concepts rather than the reality of human relationships and life (Gilligan, 1993; Noddings, 2003; Gheaus, 2018). The central component of the ethic of care is the relationship between the carer (one-caring) and the cared-for (Noddings, 2003). Noddings argued that caring was a universal human characteristic, and described this as natural caring, in other words people have a natural inclination to care for others. Ethical caring on the other hand, described the act when it is done out of duty, because it is the right thing to do. This would describe the care provided by nurses, doctors, and other healthcare workers. It will become apparent in the next chapter that Cicely Saunders, who led the hospice movement, was motivated by ethical caring, although she herself was not overtly feminist in any other way as evidenced in her publications (Saunders, 2006; Clark, 2016). The essential feature of the caring relationship is its reciprocity, the one-caring paying close attention and responding to the needs of the cared-for, who in turn demonstrates recognition of the carer's role (Noddings, 2003). It is evident in this brief summary of the ethic of care, how far removed it appears to be from the somewhat abstract deontological principles that have been proposed by Beauchamp and Childress for more than 40 years (Beauchamp and Childress, 1983; Beauchamp and Childress, 2019).

2.6.5 Summary

In this study, I am exploring how doctors' values about good medical care are formed. In particular, I am interested in the attitudes of the members of two specialties towards assisted dying. In this section I have offered three conceptual frameworks which can be used to help develop an understanding of these questions and each framework has its strengths and weaknesses. In some ways, the ethic of care is the easiest to understand. It seems intuitive that people have an inbuilt 'natural' caring side, which leads them to form relationships with each other. Noddings spoke of the carer responding to the needs of the cared-for (Noddings, 2003), and implicit in this is a problem, when considering requests for assisted dying. The assessment of 'needs may involve more than merely acquiescing to the request from the cared-for, and this would involve the personal values of the carer, in this instance a doctor. Ethical care, therefore, in describing the duty of the doctor, implies that she could interpret the needs of the patient according to her own personal values. Caring alone does not give an answer. Communitarianism is also based on the importance of relationships between people but views the interaction from a different perspective. Of the three frameworks, communitarianism offers the most direction to its followers in how to behave. This is because a communitarian society defines the good, and expects its members to follow its guidance (Kymlicka, 2002). In relation to the subject matter of this thesis, communitarianism encourages the members of their society to support and nurture each other and protect the vulnerable, and for this reason, it is opposed to assisted dying. The other relevant aspect of communitarianism is its respect for traditional structures, such as religious faith. In this country, the Christian faith generally teaches its members to reject assisted dying because of the sanctity of life. The 'principles' approach offers a more theoretical analysis of how moral decisions might be made. It can also offer a framework by which individual ethical dilemmas in healthcare could be interpreted and analysed. It has become one of the core elements of the undergraduate medical ethics curriculum (Gillon, 1986; Ashcroft *et al.*, 1998; Doyal and Gillon, 1998). One current academic in the field, when describing teaching ethics to medical students, has stated that ‘I refer to all of these frameworks, but people seem to pick up on the four principles as though they were a surgeon’s checklist.’ He also indicated that the more science-based students leaned towards the law as it offered more certainty to them in their decision making (Vernon, 2020).

2.7 Conclusion

This chapter sets the scene for the next one, in which I will explore the specialties in some detail, and I will also review issues around the end of life, with particular reference to assisted dying. I have introduced the concept of the orientations of each specialty and illustrated it in relation to their attitudes towards the medical encounter, and how they view good medical care.

Despite the changes in the medical curriculum over time, one of the most important features of medical education is still the apprenticeship, learning the clinical and behavioural skills of the good doctor from a senior role model (Gillon, 1986). The importance of this in shaping doctors’ values will be explored in the data chapters. More formal ‘medical ethics’ is now a mandatory part of the UK medical curriculum and it is relevant to ask how important such education is to medical students.

The other major moral influences on these doctors are those from the wider society in which they live. It is apparent that autonomy and personal choice have become the dominant values in Western liberal societies such as the UK over recent decades (Kymlicka, 2002). It is also evident that these values have become increasingly relevant in healthcare over the same period (Nettleton, 2013; Annandale, 2014; Scambler, 2018). For these reasons, it would not be surprising that doctors should hold a respect for patient autonomy highly when prioritising courses of action in individual clinical situations. However, there are other value systems, which may be relevant to some individuals, and these may conflict with this idea. Communitarianism stresses the importance of people respecting the traditions and values of the society that they live in. At an individual level too, people in a communitarian society are expected nurture and support their fellow members through their struggles, and this is relevant in the assisted dying debate.

Another potential source of influence on physicians’ values could come from the specialty that they specialise in, and this will be considered in the next chapter. Because a major part of the thesis relates to physicians’ attitudes to assisted dying, it is appropriate to explore the background to this in general, before looking at each specialty’s attitude towards it, and this will form the first part of the next chapter.

Chapter 3. The Two Specialties

In this chapter, I trace the development of the specialties of respiratory and palliative medicine from their origins, before either was a specialty that was recognised by the Royal College of Physicians (RCP), to the current time, when both are. I show how their backgrounds have influenced their attitudes towards the nature of illness and good medical practice, and this gives an insight into the differences between them. I also show how the inspirational leadership of two women, one from respiratory medicine and one from palliative, have shaped the direction of each specialty at a critical time in their development. I start with the RCP, which governs the training of both specialties. As there are many similarities in the RCP approach to medicine to that of respiratory medicine, I will then continue with that specialty. Finally, I will consider palliative medicine, which was incorporated relatively late into mainstream medicine, but at the same time has retained some unique features which set it apart it from other specialties.

3.1 Physicians and Respiratory Medicine

In the 500 years since the RCP was formed, its structure and function have changed to match the needs of its members and fellows (G N Clark, 1964), and hopefully the changing needs of society. While it started as an elitist organisation of gentlemen physicians, intent on maintaining their monopoly on medical practice, it has evolved into a more inclusive, but still intellectually driven body. The RCP advocates a biomedical approach to illness, delivered in a patient centred way, taking guidance from several advisory committees of a collegial nature (Waters, 1989; Parkin, 2002; Royal College of Physicians, 2019b). The College adopts a relatively liberal attitude towards assisted dying, as evidenced by its recently expressed neutral stance on the issue (Royal College of Physicians, 1993; Royal College of Physicians, 2019a). Respiratory medicine developed as a specialty within the RCP, and it shares most of its values about good medical practice. As a specialty, it does not offer any specific guidance on ethical issues, but the respiratory medicine curriculum does require the trainees to be familiar with the principles of medical ethics (Joint Royal Colleges of Physicians Training Board, 2020b).

3.1.1 History of the RCP

The Royal College of Physicians of London was founded in 1518 by a Royal Charter from King Henry VIII (Clark, 1964; Royal College of Physicians, 2019b). It initially viewed itself as an academic body for physicians, who all possessed university degrees. This contrasted with the trade guilds that existed for the surgeons and apothecaries, and as such, the RCP was elitist in the extreme. The original organisational structure of the RCP was of a president and seven other Elects. [3] The president was elected by the Elects, from within their own ranks. This traditional patrimonial structure (Weber, 1978) continued until early in the nineteenth century, when a more transparent and democratic process for electing the president was agreed (Clark, 1964) [4]. In the early years, the principal function of the Elects was to examine for and grant extra-licences to permit the legitimate practice of medicine throughout England and Wales. In this way they validated their members over other practitioners, who lacked the benefits of a university medical degree (Porter, 2006). Although the College initially restricted admission to the graduates of Oxford and Cambridge universities, from 1835, male graduates of other British universities were also eligible to be admitted (Royal College of Physicians, 2019b). The first female licentiate was admitted in 1910, the first female fellow in 1934 and the first female president in 1989 (Royal College of Physicians, 2019b). This reflects Western society's attitudes to the emancipation of women in general and a softening of the discriminatory attitude towards women in medicine over the same period.

The Medical Reform Bills of 1858 and 1886 resulted in the formation of The General Medical Council (GMC) as the regulatory body for medical practitioners (Stacey, 1992; Porter, 2006). This provided state-sponsored obligatory registration, which defined those who could and could not practice legally. In doing so it legitimised the medical monopoly that still exists today (Nettleton, 2013; Annandale, 2014; Scambler, 2018). Although the GMC was responsible for the regulation of doctors, it did not offer specific ethical guidance, largely

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[3] The Elects were appointed for life, on the basis of seniority within the RCP, and between themselves and the president, they controlled all of the decisions and activity of the college. Clark, G.N. (1964) *A history of the Royal College of Physicians of London*. Oxford: Oxford, Clarendon Press for the Royal College of Physicians.

[4] The RCP president is now elected for a period of three years by the fellows of the college. He/she presides over the Council, which provides both professional and clinical policy to its members and fellows. The Council has 42 members, of whom one is a 'lay' member.

leaving that function to the British Medical Association (BMA), which had been formed in 1856 and describes itself as the trade union and professional body for UK doctors (British Medical Association, 2019).

With the advent of the GMC, the RCP had relinquished its regulatory role and largely focussed its attention on the training of physicians and the maintenance of their medical and professional skills. The RCP also developed a committee to respond to issues of ethical significance, with the formation of the Committee on Ethical Issues in Medicine (CEIM) in 1985 (Royal College of Physicians, 1985). Its initial remit was to exist as a central reference point for hospital research ethics committees. However, it has widened its scope over time, to include a broader range of issues of ethical importance to medicine and society. These include end of life dilemmas and assisted dying, and the CEIM provides evidence and guidance to the RCP council, as will be discussed later.

In 1964, the Committee on Consultant Training of the RCP proposed specific schedules for the training of consultants in various medical specialties, and so began medical specialisation as is recognised today (Royal College of Physicians, 1964). In doing so, the RCP both acknowledged groups of physicians with similar areas of clinical practice, but also reinforced the biomedical 'disease-centred' model of care that dominates Western medicine. Amongst this first group of specialties was 'General Medicine with Special Training in Chest Diseases' (Royal College of Physicians, 1964; Health Education England, 2019; Joint Royal Colleges of Physicians Training Board, 2019a). The specialty re-branded itself as respiratory medicine in the early 1980s (Turner-Warwick, 1982). To understand modern respiratory medicine and its doctors, it is helpful to explore the background that led to the recognition that the treatment of diseases of the chest should become a formal speciality within the RCP.

3.1.2 Chest diseases and doctors

Current day respiratory physicians are concerned with patients with diseases of the lungs and the chest wall, and with people with breathing difficulties. Up until the end of the nineteenth century, these diseases were mostly infections of the lungs; the commonest of these being pneumonia and tuberculosis (TB). Although formal sub-specialisation in medicine was not recognised by the Royal College of Physicians (RCP) until the 1960s, physicians did to some extent limit the scope of their practice before then and develop expertise in particular areas. For instance, William Munk, who published an early work on care for the dying (Munk, 2018) had also a particular interest in smallpox (Hughes and Clark, 2004).

Before the development of antibiotics in the mid twentieth century, pneumonia was an acute and often fatal illness. Other than symptomatic support, no specific treatment was available, and patients either survived through their own host defences, or they did not. On the other hand, tuberculosis (TB) held a more prominent place in the mind of the public and in every day medical practice. This was because of its chronicity and the visibly progressive decline of its sufferers, as well as the romanticisation of the consumptive death as recorded in the literature and other artistic works of the time (Bynum, 2012). Sadly, the discovery of its cause by Robert Koch in 1882 did not lead to an immediate cure for TB. Before this time management of the consumptive patient would be based on fresh air, rest and diet (Bryder, 1988; Bynum, 2012). The recognition that TB was infectious and more prevalent in overcrowded poorer urban communities led to two responses, the isolation of TB patients from their community, and improvements in the provision and quality of housing (Bryder, 1988). Isolation was largely provided in sanatoria. The concept had originated in Germany in the 1820s, and was adopted in Britain later in that century (Brunton, 2019). These institutions provided residential care for those suffering from TB. The more exclusive (and expensive) sanatoria would be found in the Alps, whilst those at the other end of the spectrum were offshoots of the Poor Law infirmaries and were situated outside British cities (Dormandy, 1999). Although for some people, the consumptive death was viewed as a romantic one, for the majority, having TB carried a social stigma and those suffering from it would be isolated away from the centres of population. A sanatorium would have a hierarchical organisation headed by the medical superintendent. Descriptions of these individuals are characterised by words such as ‘disciplinarian, autocratic, benevolent dictator’ (Bryder, 1988: 203-4). These descriptors have some resonance with the wise medical paternalist that was described in the previous chapter as a role model for younger doctors and trainees (Gillon, 1986). There were various false dawns in drug treatment of TB until the introduction of streptomycin in the late 1940s. Another approach was surgery. Various techniques, including resection of the infected lung and interventions to collapse the affected lung to deprive it of oxygen were offered, with variable success (Turner-Warwick, 2005). These procedures reached a peak in the mid-1940s and continued into the early

1950s, when they were superseded by drug treatment (Bryder, 1988; Dormandy, 1999). It is evident that the sanatoria and their staff viewed their own role in terms of treatment and containment of TB patients, rather than places for the palliation of symptoms and terminal care, although many TB patients did in fact die in the sanatoria (McCarthy, 2001). Apart from the sanatorium, the other important institution of the time was the TB dispensary, which provided facilities for the outpatient supervision of patients. This would include nutritional advice, contact tracing and x-raying the immediate family contacts to detect other potential TB sufferers. When drug treatment had become available, the TB dispensary also provided prescription and supervision of the treatment.

The doctors involved in the care of TB patients were mostly working in sanatoria, local authority hospitals and TB dispensaries. At that time, in the 1950s-1960s, chest medicine was not a prestigious specialty within medicine. The reason for this was that as TB was more prevalent in crowded urban communities, the patients tended to be poorer and received their care in the Poor Law institutions and TB dispensaries, rather than through private practice. In contrast, heart and neurological disorders were not restricted to the poor, so there was a greater potential for private practice in cardiology and neurology. In his article on the history of respiratory disease management, Geddes wrote that chest clinics ‘were alongside but separate from hospitals and endured professional snobbery. General physicians looked down on chest physicians (‘Chest – yes, physician – never’) before the systems were integrated in the 1960s. Today the lung specialist is often the best general physician’ (Geddes, 2016: 397).

It was out of this environment that respiratory medicine arose. Margaret Turner-Warwick, one of the subsequent champions of respiratory medicine as a mainstream academic medical discipline, charted her own career from having treatment for TB as a medical student in the late 1940s to becoming Professor of thoracic medicine at the Cardiothoracic Institute and then the first female President of the RCP in 1989 (Turner-Warwick, 2005). The academic pedigree of respiratory medicine developed through the work of the chest physicians from the late 1940s onwards. The clinical trials of anti-tuberculous chemotherapy introduced the concept of randomised controlled trials (RCT), which have since become the cornerstone of evidence-based medicine (Turner-Warwick, 1982; Scadding, 1999; Chalmers and Clarke, 2016; Geddes, 2016). Other major contributions were the understanding of the mechanisms of breathing and breathlessness, through respiratory physiology (Campbell, 1955; Campbell and Howell, 1963; Gibson, 2004), and the epidemiological evidence of the harmful effects of cigarette smoking (Doll and Hill, 1956; Doll *et al.*, 2004).

The point of this description is to show how the doctors in respiratory medicine have developed the specialty since the middle of the twentieth century. It has moved from the unscientific and unsuccessful treatment of an unfashionable disease of the poor, to be at the forefront of academic clinical enquiry, clinical trials and the evidence-based medicine that is now the gold standard in healthcare (Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016).

3.1.3 The British Thoracic Society

The British Thoracic Society (BTS) was formed in 1982 following the merger of its two parent societies, the Thoracic Society and the British Thoracic Association (BTA) (Turner-Warwick, 1982). Historically, the Thoracic Society had a restricted membership of respiratory scientists and thoracic surgeons, whilst the British Thoracic Association's roots were in the management of TB and conducting the clinical trials that revolutionised its treatment. Turner-Warwick, as the first president of the BTS wrote about its future direction in the following terms.

> *'While there is unanimous agreement that the primary purpose of the new society is for the exchange of scientific ideas there will be much debate on what stand should be taken in other spheres, and differing views have already been expressed. The question of how far the society can contribute to the maintenance of professional standards in Britain will certainly arise … The society must also decide how it can best relate to the specialist subcommittees of the Royal Colleges. Many exciting and innovative opportunities for creating better standards in both staffing and training lie here.' (Turner-Warwick, 1982: 322).*

The sentiments expressed in these words, written 37 years ago, are reflected on the current BTS website and describe the values of the specialty (British Thoracic Society, 2019). Turner-Warwick was outlining her vision of the modern respiratory physician, holding equal scientific and professional credibility with physicians of the other, previously more prestigious, medical specialties. She also referred to the importance of an ongoing relationship with the RCP, and the need to improve standards of medical care. Her own contribution was recognised in 1989, when she was appointed as the first female president of the RCP.

Like the RCP, the BTS operates with a collegial structure of advisory committees. For instance, amongst them the Standards of Care Committee focusses on guideline development and the production of quality standards, confirming their commitment to EBM (British Thoracic Society, 2020). The main scientific journal for the specialty in the UK is 'Thorax', which has been published since 1946. In 2019, its impact factor [5] was quoted as being 10.307, compared with 'Diabetes' (7.273) and 'Palliative Medicine' (4.956) (BMJ, 2019). This can be interpreted as further evidence of respiratory medicine's improving academic credentials in the UK and the value that the specialty places on the application of a scientific approach to the study of respiratory diseases.

3.1.4 Summary

Although respiratory medicine arose out of the humble origins of the TB sanatoria and the poor law hospitals, its doctors were physicians, and the discipline was amongst the original group given specialist training status by the RCP in 1964 (Royal College of Physicians, 1964). Since then the specialty has developed clinical and scientific respect in parity with the other mainstream medical disciplines. The values of respiratory medicine as a specialty and its physicians, in terms of what is 'good medicine', are very much in line with those of the RCP. Illness is interpreted in terms of diseases, which should be approached from a biomedical perspective, with a view to treatment of the disease. This treatment should be justified by evidence, based on properly conducted clinical trials, in other words the specialty values evidence-based medicine (Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). Both the RCP and the BTS operate as organisations with a collegial committee structure, in which all members and their opinions are treated with the same respect (Waters, 1989). Such respect for individual opinions is characteristic of the liberal egalitarian societies as described by Kymlicka (2002) and were referred to in the preceding chapter. I shall be referring to the RCP's liberal values later in this chapter in relation to attitudes towards assisted dying, a topic that the BTS has not expressed any opinion on at all. I shall be referring to this topic

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[5] The impact factor of an academic journal is a scoring system that measures the yearly average number of citations that articles published in the preceding two years in that journal have received. It is widely used as a measure of the quality of a journal. Those with higher impact factors are often thought to be more important than those with lower scores.

again later in this chapter, after I have reviewed the development of the speciality of palliative medicine, which arose in very different circumstances.

3.2 Palliative medicine

Palliative medicine became a medical specialty with RCP recognition for higher specialist training in 1987 (Hillier, 1988; Overy and Tansey, 2013; Clark, 2016). The development of the specialty has largely been attributed to the inspiration and leadership of Cicely Saunders, who is widely accepted as the person who initiated the hospice movement (Twycross, 2005; Hanks, 2010; Clark, 2016; Stolberg, 2017). This section will chart the progress from Saunders' early ideas of hospice-based care for people dying from cancer through to modern palliative medicine. In fact, it was Saunders' dissatisfaction with the management of people dying from cancer within the NHS, that stimulated her to take her chosen path in the first place (Saunders, 2006; du Boulay and Rankin, 2007).

3.2.1 Care for dying people

To appreciate Cicely Saunders' contribution to end-of-life care and the subsequent development of palliative medicine in the UK, it is useful to explore how care for dying people had evolved over the period up to the early 1950s, when she started her work in that area. During the nineteenth and early twentieth centuries, several social, environmental and medical developments had impacted on illness, disease and death, and the effect of these was to change the demographics of death in a number of ways (Kellehear, 1998; Kellehear, 2007; Scambler, 2008; Clark, 2016; Scambler, 2018). It is evident that these changes had been developing throughout the nineteenth and early twentieth century. Firstly, from a social perspective, death had shifted from being an important family and spiritual event, occurring in the home and accompanied by the rituals of the time to a lonely and uninformed experience in hospital (Ariès, 1976). In his assessment of Aries' work, Kellehear wrote:

> *Aries was reacting to his contemporary situation. This was the situation and circumstances of dying in the mid-twentieth century, a time when dying had come to be seen as a medical failure. Hospitals isolated the dying from other patients. Doctors felt that knowledge of dying would so shatter a person's hopes and mental stability …*

> *the dying in Aries' time were disempowered people who were often left to die alone, and ignorant of their fate until hours from it. (Kellehear, 1998 : 289)*

The second change, which had also been progressive over more than one hundred years, was that people were living longer, and more were dying from chronic diseases, rather than acute infections such as pneumonia, cholera and dysentery (Scambler, 2018). By the mid twentieth century, tuberculosis was in decline as a cause of death, and cancer deaths had become more prominent. These changes led to patients experiencing a slower and more distressing dying process, both physically and emotionally. Against this backdrop there had a few physicians who recognised the importance of good care for the dying and who wrote about their experience in this area (Clark, 2016; Munk, 2018). An alternative environment for those whose death could not be managed in their own home would be one of the homes for the terminally ill. These were charitable, religious organisations, which were staffed by women, who were often nuns. Their focus was primarily for the salvation of the soul and 'a safe passage to eternity' (Clark, 2016: 36), although some received visits from physicians to advise them about how to manage the troublesome symptoms of their patients. With the advent of the NHS in 1948, little specific attention had been turned towards to terminal care. However, two influential reports on services for this client group were published in the ensuing years, pointing out the deficiencies that existed at the time in the UK (Marie Curie Memorial Foundation, 1952; Glyn Hughes, 1960). The first of these focussed on people dying at home, and the poor circumstances of their deaths (Marie Curie Memorial Foundation, 1952) and the second on the lack of service organisation for people dying from cancer in all the environments just described (Glyn Hughes, 1960). This was the backdrop for Cicely Saunders in her mission (du Boulay and Rankin, 2007; Clark, 2016).

3.2.2 Cicely Saunders

In this section I shall outline the unique contribution that Cicely Saunders made to develop what is now known as the specialty of palliative medicine. In the following paragraphs, I will focus on the different aspects of her that defined her qualities.

Cicely Saunders was a woman driven by vocation, faith, and a scientific mind. Despite her parents' academic aspirations for her, she gave up her Oxford degree course after one year to enter nursing at St Thomas's Hospital, at the outset of the second-world war. Her biographer subsequently described how happy and fulfilled she was as a nurse at this time (du Boulay and Rankin, 2007), so, it seemed that she had found her role in life. Sadly for her however, problems with her back forced Saunders to leave nursing immediately after qualifying, and she had to look elsewhere for her caring vocation. She chose social work, and subsequently qualified as an almoner. Once qualified, her first post would be with cancer patients at St Thomas's Hospital in autumn 1947 (du Boulay and Rankin, 2007; Clark, 2016). In parallel with her professional journey, Saunders was also on a spiritual journey, culminating in a conversion to evangelical Christianity during the summer of 1945. She recounted that 'at that moment I felt that God had turned me round and that it was all right. It was for all the world like suddenly finding the wind at your back instead of battling against it all the time.' (du Boulay and Rankin, 2007: 28). This Christian faith remained with Saunders throughout her life, although she became less evangelical as time went by.

In the autumn of 1947, as a newly qualified almoner with a recently acquired and passionate Christian faith, Saunders met and formed a short but powerful relationship with one of her patients, David Tasma. Tasma was a Polish Jew, although he was agnostic, and he was suffering from terminal cancer. du Boulay wrote: 'He was admitted to the Archway Hospital in Highgate and it was there that the professional relationship developed into a deep friendship. This soon ripened into love' (du Boulay and Rankin, 2007: 34). The relationship seems to have been based on deep and meaningful communication between them. Saunders had realised that the care for people dying from cancer was mostly unsatisfactory and she talked with Tasma about this. It was this relationship which gave her the impetus for her subsequent career. Her project would eventually include the development of a hospice for end-of-life care, the provision of education of others and research into better ways to care for people who were dying from cancer. Tasma himself died in early 1948, leaving a bequest for £500 to Saunders for her project, with the words: 'I'll be a window in your home' (Saunders, 2006: 127). Saunders understood this to convey that the window symbolised communication between her ideals, as exemplified by the hospice (which was to be called St Christopher's) and the wider community.

Following Tasma's death, Saunders began to work at St Luke's Hospice as a volunteer nurse, so that she could learn about care for dying people, as it was practised at the time. During this time, she was persuaded that to achieve her longer-term aim, she should in fact become a doctor, and so she became a medical student at St Thomas's Hospital qualifying as a doctor in 1957. From 1958 until 1967 Saunders undertook a research fellowship in clinical pharmacology based at St Joseph’s Hospice. During this time, she developed her ideas about her chosen vocation; care for the dying and the hospice, where it would happen. She also published widely, and in one of her earliest papers in 1959, she described her objections to euthanasia for the first time (Saunders, 1958; Saunders, 1959; Saunders, 1965; Clark, 1998; Clark, 1999; Saunders, 2006).

Through a study of her own publications, it is possible to identify Cicely Saunders’ personal and professional values, and how she related them to the model of care that she was developing (Clark, 1998; Clark, 1999; Saunders, 2006; du Boulay and Rankin, 2007). It is also possible to trace how her model was translated into the principles of modern palliative care.

Saunders was primarily concerned with improving care for people dying from cancer. The term ‘palliative care’ did not in fact enter the literature until 1974 (Clark, 1999). Before this time, Saunders largely described ‘terminal care’. In her early publications, it is evident that her Christian faith was very important in the formation of her values relating to three separate areas. These were the St Christopher’s Hospice project, the importance of the period approaching the end of a person’s life and euthanasia. In her later work, the importance of faith, or more specifically Christian faith, appeared to have become less prominent, and replaced with the notion of spirituality and the importance of considering each person as a member of the (human) community, whose life should be valued and nurtured until its natural end (Clark, 1998).

When she was making plans for the St Christopher’s Hospice project, Saunders assembled a group to help her in the enterprise (du Boulay and Rankin, 2007; Clark, 2016). Most of these people were of the Anglican faith and one of the earliest questions was whether St Christopher’s should primarily be a Christian Community, which had been her initial thought. In the event Saunders was persuaded that the Hospice should mainly be a medical concern with a Christian inter-denominational foundation, rather than a religious one. However, the notion of a ‘community’ at St Christopher’s persisted and the importance of the relationship between its members was maintained. It is also evident that Saunders’ Christian faith underscored her personal values and her views on how end of life care should be delivered. She saw the dying process, the hours or days leading up to death, as an important and necessary time, which should not be cut short intentionally. She had already observed that in hospices, her cancer patients would only survive for days or weeks anyway. She also explored the value of suffering from a Christian viewpoint. In 1965, she wrote that: ‘The last stages of life should not be seen as defeat, but rather life's fulfilment. It is not merely a time of negation but rather an opportunity for positive achievement … We have the endless fascination of watching each individual come to terms with his illness in his own way and come along his own path to life's ending' (Saunders, 2006: 79-80). As time went by, Saunders' Christian interpretations of the dying process became less obvious, to be replaced with a softer, secular spiritual interpretation. Despite this change, she continued to express the importance of this period at the end of life as a time for personal growth. Saunders' objections to euthanasia had been first expressed in 1959, in her first publication as a research fellow at St Joseph's Hospice (Saunders, 1959). This attitude persisted throughout her career and she wrote about the issue on several occasions throughout her career (Saunders, 1992; Saunders, 1995; Saunders, 2003). In her earlier publications, she used both theological arguments and empirical ones to support her views. She described how the Christian duty is to alleviate suffering and thereby allow a natural and peaceful death, and she also contemplated the value of suffering from a Christian viewpoint (Saunders, 2006). In 1989, she wrote:

> *The Christian concern for personal freedom includes a concern that there should be no implied pressure to end life. A right to die could all too soon become a duty to die and life that is becoming burdensome be seen as no more than a burden to others, a burden one has no right to inflict on them. The hospice movement stands firmly against any legislation of "active euthanasia" however hedged about by safeguards and procedures. (Saunders, 2006: 226)*

It is interesting how she turned round the notion of right into duty, implying that the idea of being a burden was imposed by society on individuals, rather than arising from within the people themselves. Her main empirical argument was that requests for assisted dying were made by people with suffering due to unrelieved symptoms and that 'with the development of modern methods of palliative care, legislation of voluntary euthanasia is unnecessary' (Saunders, 1992: 3). Whether this is really true will be discussed later. I will provide a more detailed analysis of the euthanasia debates in the next chapter; the point of this discussion is to show that Saunders' views were underpinned by a strong Christian faith.

The professional values that Saunders expressed are an interesting combination of morality based on the importance of care and relationships, but also of the necessity for an empirical scientific approach to symptom control. I shall consider these from five aspects: the caring relationship, open awareness, holistic care, when biomedicine is important and the value of the final journey.

The intimacy of Saunders' relationship with David Tasma has already been described (du Boulay and Rankin, 2007). Whilst she was working at St Joseph's Hospice, Saunders encountered another Polish patient, Antoni Michniewicz, who was a devout Catholic and he was also dying from cancer. Their relationship was described as intense and loving, and a quote from Saunders' own diary read:

> *30.07.60: I did tell him that I loved him – rather – but that the lord loved him much more and that was what mattered not me. He made me repeat it to be sure. And he just smiled. And then I said good night and kissed him swiftly – hoping that the lord had put up a screen. O sleep well beloved.* (Saunders in: du Boulay and Rankin, 2007: 78)

It is relevant to note both the passion that she felt towards her patient, and her religious justification for those feelings. There seems to be a stark contrast between the passionate emotions expressed in her diary and Saunders' focus on the rational empirical approach to the use of opioids that she referred to in her research and publications (Saunders, 2006). For Saunders, a close and caring relationship between doctor and patient was vital. She also recognised that care involved more than the biomedical aspects of drugs and disease processes, and embraced the social, psychological, and spiritual aspects of the patient's experience of suffering. She also acknowledged the importance of the members of the patient's own 'team', the family, and friends. Certainly, conventional medicine does not encourage the intimacy with her patient that Saunders described in her diary. Doctors often remember 'special' patients, those with whom they develop a close understanding, or recognise shared values, but (medical) convention would stop them short of declaring love or kissing them (General Medical Council, 2013).

One aspect of the relationship between doctor and patient that Saunders felt was important was 'should a patient know?' She first wrote about truth telling in 1959, and returned to the topic in 1967, when she referred to the work of Glaser and Strauss relating to open and closed awareness of dying (Glaser and Strauss, 1965; Saunders, 2006). She concluded that a close relationship held the answers to the two most important questions, which were:" What do you let your patients tell you?" and "What shouldn't you tell your patients?" (Saunders, 2006: 94). By understanding the patient's perspective, it should be possible to share the information in an appropriate way.

Another characteristic that was important to Saunders in terms of her model of care was what is now known as holistic care. This was described in the previous chapter and although she did not use the term as such, her concept of ‘total pain’, originally described in 1981, expressed the exact principles of the holistic approach.

> *‘Pain can blot out the world, cut off all true communication and perpetually renew a vicious cycle of pain, fear, tension and further pain. It is no exaggeration to term a patient’s suffering as ‘total pain’ and it may help to divide it into physical, emotional, social and spiritual components in order to assess, understand and treat these people and their feelings better.’ (Saunders, 2006: 166)*

Within this holistic approach, Saunders also adopted a scientific and biomedical approach to the management of specific symptoms such as pain (Saunders, 1965; Saunders, 1967; Saunders, 1996). This included a formal investigation into existing clinical practices that she had observed during her attachments at different hospices, such as the use of the ‘Brompton cocktail’ and whether the regular administration of opioid analgesics was more effective than ‘as needs be’ (Twycross, 1973; Saunders, 2006; Clark, 2016). She networked widely with others in the field, particularly in the USA (Clark, 2016), and she also supervised a research programme into the rational use of morphine and other opioids (Twycross, 1973).

Although earlier in her career, Saunders described the journey at the end of a patient’s life from a faith perspective, towards the end of her career, she summarised her views on the importance of the natural dying process in more secular terms. In 1998 she wrote:

> *‘If he is recognized as the unique person he is and helped to live as part of his family and in other relationships, he can still reach out to his hopes and expectations and to what has deepest meaning to him and end his life with a sense of completion.’ (Saunders, C in Doyle et al., 1998: viii).*

Apart from reaffirming the importance of living life to its natural end, she was also expressing the traditional Christian communitarian attitude of valuing people as members of their own family and local community.

It is apparent that UK palliative medicine has embraced all the principles of care that I have just outlined as being of importance to Cicely Saunders. This is evident in textbooks (Doyle *et al.*, 1993; Doyle *et al.*, 1998; Cherny *et al.*, 2015) and in the training programme for palliative medicine (Joint Royal Colleges of Physicians Training Board, 2019b; Joint Royal Colleges of Physicians Training Board, 2020a).

3.2.3 The hospice movement

On its opening, Cicely Saunders became medical director of St Christopher's Hospice and she was active in supervising her own research and teaching programmes. St Christopher's ran an extensive education programme and received numerous visits from people planning their own hospices. Saunders herself continued to travel widely to proselytize her ideas on the management of terminal illness (Clark, 2016). The terms 'terminal care' and 'hospice care' were largely replaced by 'palliative care' in the UK in the 1970s, following Balfour Mount's visit to St Christopher's in 1974 (Mount, 2003). Over the next twenty-five years there was an exponential increase in the number of hospices in the UK, from less than 15 in 1965, to more than 150 in 1991 (James and Field, 1992). There were similar developments in the provision of home-care services and hospital support teams as the potential of Saunders' approach was realised.

The development of the palliative care movement, as described above, is attributable to Cicely Saunders' leadership, which has been described by several authors as charismatic (James and Field, 1992; Clark and Seymour, 1999; Foley, 2005; Seymour *et al.*, 2005; Twycross, 2005). The significance of this particular description goes back to the work of Max Weber and his theories on legitimate domination in society (Weber, 1978). It is important at this point to explore this in more detail, as it is relevant to understanding the development of palliative medicine in the UK after Saunders' retirement.

Weber described three types of societies, with different structures of power and leadership. These he termed 'traditional', 'rational' and 'charismatic'. Traditional domination was based on the principle that individuals were obedient to those in authority because that is what had always happened. Examples included 'patriarchal', 'patrimonial' and 'feudal' systems. Rational domination, also described as legal-rational or bureaucratic, was in Weber's opinion the major and most stable type of structure in Western society. It was based on a system of rules and laws, which were enacted by a bureaucratic, hierarchical organisation. The third was charismatic domination. A charismatic leader gained domination by inspiring her followers through her ideas and actions. They followed willingly without the need for rules or coercion. The problem with this type of leadership was that in order to maintain dominance, the charismatic leader needed to continually demonstrate her inspiration to convince her supporters to keep following. Weber noted that generally, purely charismatic movements tended to be short lived. As the power of the leader waned, either a new leader with similarly inspirational qualities and ideas needed to come forward, or structures were put in place to maintain the principles of the original leader. Weber described the latter as the routinisation of a charismatic movement. In this process, the values and principles of the charismatic leader were enshrined in bureaucratic rules and the organisation became legal-rational to maintain those principles (Weber, 1969; Weber, 1978; Parkin, 2002; Kalberg, 2017).

One of the key features of the success of the hospice movement was that it had developed outside of the NHS in response to the inadequacies of care for the dying within that organisation. Some of the hospices that were developed during this time, such as St Columba's Hospice in Edinburgh, Countess Mountbatten House in Southampton and Sobell House in Oxford were led by their own 'mini-charismatic' leaders, who as will be seen, were also instrumental in the development of palliative medicine as a medical specialty in this country. These were Derek Doyle, Richard Hillier and Robert Twycross respectively (Overy and Tansey, 2013; Clark, 2016). Saunders retired from her clinical duties in 1985, although she remained active in her writing and teaching and her influence was ever-present. The next stages for palliative care would be for its doctors to form a specialist society and the incorporation of their practice into mainstream healthcare by the acknowledgement of palliative medicine as a UK medical specialty.

3.2.4 The Association for Palliative Medicine

The formation of the Association for Palliative Medicine (APM) in 1986 (Doyle, 2015) was led by the three senior hospice doctors mentioned above. It had already been recognised that there was a need to bring together like-minded physicians for mutual discussion and education, and for there to be a representative body for these doctors. They were beginning to come to terms with working in a specialty which had been so dominated by one individual, who although retired was still a commanding presence amongst them. They needed to replace the charismatic leadership of Saunders with bureaucratic structures that would maintain her values and ideals within the NHS. Robert Twycross, a member of the inaugural APM executive committee wrote:

> *And I remember talking … should we have some national organization? But we were also living under the shadow of Cicely Saunders and we didn't want to do anything to*

> *offend her, which I think is fair enough, and she didn't come forward and say: 'Here is a national organization.' So I think there was a reticence. (Twycross in Clark, 2016: 152).*

The hospice nurses had already formed a professional group, so the decision was made that the APM would represent the doctors working in palliative care environments. By restricting membership to doctors, the APM strengthened the separation of palliative medicine (what doctors do) from palliative care (the broader, multi-professional subject area). Doyle (2015) noted that even at that time there were also some tensions between the doctors with 'physician' qualifications (Member or Fellow of the Royal College of Physicians: MRCP or FRCP) and those with 'general practitioner qualifications' (Member of the Royal College of General Practitioners: MRCGP), as both were being appointed to consultant posts. The reason for this tension was that those with physicians' qualifications viewed them as being superior to those of the GPs. To this day, palliative medicine is the only specialty of the RCP that accepts doctors with GP qualifications (Joint Royal Colleges of Physicians Training Board, 2019a). Despite these tensions, the APM was formed and as will be seen, it has adopted Cicely Saunders' values almost in their entirety, whilst developing some others.

The APM expresses a distinct set of priorities, as can be found on its website (Association for Palliative Medicine, 2019a). The three areas that dominate are educational events, workforce issues and ethics, but not research or science. In terms of education, they offer an annual congress, and annual ethics study days, amongst other specific topic related study days. Ethical deliberation has always been a core issue within palliative medicine, and within that, assisted dying has been the most prominent topic of discussion. This will be considered in more detail in the following chapter.

3.2.5 Palliative medicine as a specialty

The recognition of palliative medicine as a specialty by the Joint Royal Colleges and of palliative medicine as a training programme within the Joint Committee on higher Medical Training (JCHMT), occurred in 1987. This was achieved with the assistance of Dr Gillian Ford, the deputy chief medical officer of England, who had been a medical student with Cicely Saunders and had worked as a doctor at St Christopher's (du Boulay and Rankin, 2007; Clark, 2016). The significance of this is that in the process, a specialty which had developed over 20 years outside the NHS, under charismatic leadership, joined an academic organisation with nearly 500 years history.

It should also be noted that the specialty did not just stay still and merely maintain Saunders' ideals within the NHS and the voluntary sector. Palliative medicine sought to expand its values and practices into other areas of healthcare. One of the most notable of these was the concept of supportive care (National Institute for Clinical Excellence, 2004; Thomas and Richardson, 2004). This aimed to apply an approach, based on individual needs, to the management of patients earlier in their disease trajectory, when they might be receiving disease modifying, or even curative treatments (Ahmedzai *et al.*, 2012; Bourke *et al.*, 2019). It acknowledged that the treatments themselves might be a major source of suffering (Snowden *et al.*, 2011), but also, that holistic care, involvement of families and carers, and close links with specialist palliative care were also crucial (Ahmedzai *et al.*, 2004; National Institute for Clinical Excellence, 2004). In this way, the principles of palliative medicine were further integrated into mainstream medicine.

3.3 Summary

In this chapter, I have described the evolution of the two medical specialties that are the subject of this thesis. Although the doctors in each specialty share many common values as they are all UK doctors and physicians, their values are also shaped by the particular features of each specialty. Respiratory medicine, with its focus on diseases of the chest, adopts a biomedical approach towards the treatment of these diseases, based on scientifically designed clinical trials and statistical evidence of the efficacy of the treatment. With a few exceptions, such as the infections, when the aim is cure, respiratory illnesses are chronic. Therefore, under these circumstances the aim of treatment is twofold, the prolongation of life and improving its quality. The doctors in the specialty value evidence-based practice with the production of guidelines and audits of their practice. Although the RCP as an organisation considers moral issues of relevance to medicine, the BTS limits its attention to the relatively value neutral issues that have just been described. In contrast, palliative medicine looks to relieve people's suffering by using a holistic approach, although they apply biomedical principles to the assessment and management of troublesome symptoms. Palliative physicians try to adopt a care philosophy very much in line with that of Cicely

Saunders, although they do not necessarily share her Christian faith. They aim to explore and understand the lived experience of their patients' suffering (Carel, 2016). Ethical deliberation is an important component of palliative practice and is in part guided by communitarian and relational values. These include the intrinsic importance of the person within her community right up to the end of her life, and the family as a key part of the unit of care.

As the stimulus for this thesis was my initial observation of differences in the attitudes towards assisted dying between the members of the two specialties, it is appropriate to consider assisted dying in some detail in the next chapter.

Chapter 4. Assisted Dying

I became interested in doctors' attitudes to assisted dying when, as a new member of the Executive Committee of the Association for Palliative Medicine (APM), I realised the vehemence of the other members' opposition to it. Although as a clinician, I had occasionally been asked to shorten a patient's life because of their suffering, I did not consider it in any depth after the request, as I knew it was illegal anyway. What surprised me was the unanimity of the other palliative medicine doctors' opinions and their enthusiasm to take on a cause, which I had never heard being discussed during my time in respiratory medicine. In this chapter, I intend to explore assisted dying in some detail. I shall start by defining the relevant terminology as I understand it from the medico-legal literature (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). I will follow this with a review of how the UK law views interventions that may actually shorten people's lives. It will be seen that some of these have been legitimised, and this itself influences medical opinion on the morality of these interventions.

Next, I turn to assisted dying, and in this section, I will use the terms euthanasia and assisted suicide as both are referred to in the literature at different times, although there are clear differences between them. For instance, Cicely Saunders tended to write about euthanasia (Saunders, 1959; Saunders, 1992; Saunders, 1995; Saunders, 2003). However all of the recent attempts to change the law in the UK, that she herself objected to, have been in relation to physician assisted suicide (House of Lords, 1994; House of Lords, 2005b). After a brief review of the history of the UK euthanasia debates, I shall outline the arguments employed by the protagonists in these debates. This will be followed by a review of the empirical data on the attitudes of different sections of the UK population towards assisted dying and whether it should be legalised. In the final section, I shall link all the preceding theory to what the organisations said, when the RCP decided to poll its fellows and members about assisted dying.

4.1 Terminology

My main area of interest is in assisted dying, in which the intention is to end the patient's life at her request. The other acts, which are relevant to the thesis, are the withdrawal or withholding of life sustaining treatments and the doctrine of double effect (DDE).

Assisted dying, which is also known as physician assisted dying (PAD), is usually understood to include either of two acts, which are euthanasia and physician assisted suicide.

Euthanasia, or more accurately *Active Voluntary Euthanasia (AVE),* describes the act of deliberately ending a person's life, at their own request. As the name implies it is an act (usually performed by a doctor) and voluntary (on behalf of the competent patient).

Physician Assisted Suicide (PAS) is the assistance of a physician (by the provision of appropriate drugs) to a patient to end her own life at her own wish. In Switzerland, assisted suicide is aided by a someone who does not have medical qualifications (Gauthier *et al.*, 2015).

In the next section, I will consider interventions which may shorten life, but are not intended to do so.

4.2 Withholding or Withdrawal of Life Sustaining Treatments, and the Law

As patients move towards the end of their lives, there are three potential interventions, which may shorten the process. These are first, the withdrawal (at the competent patient's request), or refusal of potentially life sustaining treatment (by a competent adult), second, the cessation of life sustaining treatment in an incompetent patient's 'best interests' and third, assisted dying for a competent adult who requests it. In this section, I shall consider the first two of these three in the context of UK law. The case of Tony Bland [6], who was injured in the Hillsborough football stadium disaster in 1989 and suffered anoxic brain damage resulting in his entering a persistent vegetative state, was a landmark case in the UK courts (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). In the case, both Bland's parents and his doctors wanted to stop life sustaining interventions, and the Trust applied for a declaration that it would be lawful to do so. This complex judgement legitimised the

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[6] Airedale NHS Foundation Trust v Bland [1993] AC 789 House of Lords

withdrawal of life sustaining artificial hydration and nutrition, in his case to allow him to 'end his life in dignity' (Laurie, 2016: 553). This case was important because it clarified several issues; firstly, that there should be a consistency between the law and the acceptable ethical values of society. Secondly the difference between positive acts (commissions) and omissions was clarified, and that under certain circumstances it would be legitimate to withdraw a life sustaining treatment, but never to actively end a life. Thirdly, although 'best interests' decisions should be informed by family members, the final decision about whether to withdraw a treatment would lie with the attending medical team (Laurie, 2016). The exception to this is in relation to patients suffering from persistent vegetative state (PVS). The General Medical Council (GMC) instructs its doctors that: 'If you are considering withdrawing nutrition or hydration from a patient in PVS or a condition closely resembling PVS, the courts in England, Wales and Northern Ireland currently require that you approach them for a ruling.' (General Medical Council, 2020 para 126).

The right of a competent patient to refuse any treatment was re-affirmed in the UK in 1992 in the case of *Re T* [7], which involved a pregnant woman who was a Jehovah's Witness and who refused a potentially life-saving blood transfusion. Lord Donaldson granted an appeal by the boyfriend and father of T to override T's refusal of transfusion because it was considered that her decision was 'flawed' and was not a truly autonomous judgement. In his summing up he stated that 'an adult patient who suffers from no mental incapacity has an absolute right to consent to medical treatment, to refuse it or to choose an alternative treatment' (Laurie, 2016: 76). Subsequent similar judgements of importance and relevance included *Re C* [8], in which a man who suffered from chronic paranoid schizophrenia and was in long-term care was permitted to forego a potentially life-saving amputation of a gangrenous leg. It was judged that despite his diagnosis he did retain capacity to make the specific decision about whether to have the operation. *Re B* [9] involved a quadriplegic woman, whose life was dependent on a ventilator, but she wanted it removed to allow her to die, against the opinion of the healthcare professionals treating her. Butler-Sloss P judged that continuing to ventilate the patient against her wishes constituted an assault on her and that her ventilation should be ceased.

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[7] Re T (Adult: Refusal of Medical Treatment) [1992] 4 A11 ER 469, CA.

[8] Re C (Adult: Refusal of Treatment) [1994] 1 A11 ER 819.

[9] B v NHS Hospital Trust [2002] A11 ER 449.

Similarly, the Mental Capacity Act (2005) endorsed the right of a person to make decisions in advance, when healthy, [10] to refuse potential treatments in the future if her capacity were to be lost and she were unable to decide at the time. However, although there is a legal right to refuse a treatment, there is no corresponding right to demand treatment. This is particularly relevant to this thesis. If some form of assisted dying were to be legitimised in the UK, and therefore deemed a 'medical treatment', there would be no legal obligation for any individual doctor to provide that treatment. In the context of the Abortion Act 1967, if doctors expressed a conscientious objection to abortion, they were not obliged to perform the act, but were obliged to refer the patient on to another practitioner (Herring, 2018). It is relevant to point out that in the RCP survey, which I will describe in more detail later (*4.7.1*), 24.6% of the 6885 respondents stated that they would 'be prepared to participate actively' (Royal College of Physicians, 2019c; Royal College of Physicians, 2019a). This would suggest that there are doctors in the UK who would be willing to be involved in assisting dying. Having said that, at the time of writing this thesis, both euthanasia and physician assisted suicide are illegal in the UK.

4.3 Doctrine of Double Effect

Relief of suffering is important for people as they approach the end of their lives. As pain and emotional distress are relatively common symptoms at this stage, many patients are receiving painkillers in the form of opioids, and sedatives. It is recognised that respiratory depression is potentially the most serious adverse effect of opioids (Doyle *et al.*, 1998) and overdosing with this class of drugs could result in death. Similarly, deeply sedated patients are unable to eat or drink, and without clinically assisted hydration, they too may die sooner than they would have done otherwise (Cherny *et al.*, 2015). In theory therefore, the provision of a drug for symptom control might hasten death as a foreseen, but unintended consequence.

The origin of the doctrine of double effect (DDE) has been credited to Thomas Aquinas in his justification of killing an assailant in self-defence (McIntyre, 2019). His argument was that if the intent was primarily to save one's own life (a beneficent act), then the (unintended)

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[10] ADRT: Advance Decision to Refuse Treatment. This is legally binding, and a healthcare professional knowingly ignoring it would be charged with assault.

killing of the assailant would be morally justifiable. This theory can be generalised, and the characteristics of an act that would be justifiable through DDE have been summarised as:

1. The act (treatment in this case) should be either beneficial or at least neutral.

2. Although the intent is beneficial, adverse effects may be foreseen.

3. The beneficial effect should not be achieved through the adverse effect.

4. The likelihood of the adverse effect should be proportionate to the seriousness of the problem being treated. (McIntyre, 2019)

The classic situation in which the DDE has been invoked in medical practice is the administration of opioids for pain, in the knowledge that they may depress respiration and may therefore hasten death (Gillon, 1986; Gillon and Doyal, 1999; Woods, 2007). The DDE was famously used in the defence of Dr Bodkin Adams [11], who was a GP accused of killing one of his patients by the recurrent administration of morphine. The patient was a woman who had had a stroke and who incidentally, had also made him a beneficiary in her will (Devlin, 1985). The circumstances of her demise were concerning, as the use of morphine for a stroke victim is unconventional. It is interesting and important that the judge in the case instructed the jury that a doctor ' is entitled to do all that is proper and necessary to relieve pain and suffering, even if the measures he takes may incidentally shorten life' (Devlin, 1985: 171). This judgement raises two issues, the relationship between intending and foreseeing, and the relationship between medicine and the law. Dr David Moor's acquittal in 1999 of killing his terminally ill patient with a morphine overdose, also relied upon the DDE as a defence in somewhat less controversial circumstances (Gillon and Doyal, 1999). Indeed Cicely Saunders herself had written that: 'At times we may have to involve the principle of double effect, knowing that the adequate control of terminal restlessness or pain may lead to a degree of sedation that in itself may hasten death' (Saunders, 1995: 44).

In response to the wider belief in medical circles that DDE was a common occurrence with the use of morphine, the palliative medicine community produced a robust response (Sykes and Thorns, 2003; George and Regnard, 2007; Regnard *et al.*, 2018). Their argument was that with appropriately slow dose titration, respiratory depression (and therefore death) should not occur after opioid escalation. However, there is also contradictory evidence of an

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[11] R v Adams [1957] Crim LR 365

association between shorter survival and higher opioid dose from a study of a hospice population (Portenoy *et al.,* 2006). Despite the opinion of the UK palliative community, DDE is still recognised by the legal profession as an acceptable defence if death is believed to have been hastened by the means of symptom control (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). Apart from the technicalities about the dose titration, the key to the issue is the relationship between intent to kill, and foreseeing death but not intending it. The notion of ‘easing the passing’ seems to be trying to close the moral boundary between the two. Perhaps the law is attempting to provide a pragmatic way to do so, which palliative medicine is not willing to accept. Another judgement illustrating the sympathy that the law holds for medicine in such circumstances was in the case of Dr Cox [12]. He had administered a dose of potassium chloride to one of his patients, who suffered from rheumatoid arthritis with intractable pain, and she had begged him to end her suffering. This intervention resulted in her death. The difference between this case and those of Adams and Moor was that the sole aim of Cox’s treatment was to kill his patient, as potassium chloride has no analgesic or other therapeutic effect. In finding him guilty of attempted murder (as opposed to murder), the judge was able to impose a suspended sentence rather than a mandatory life sentence, and indeed the GMC allowed him to continue to practice (Brazier and Cave, 2016).

4.4 History of Euthanasia Debates in the UK

The use of the word, euthanasia with its current meaning in the English language (as defined in 4.1), probably dates back to the late nineteenth century (Fye, 1978). It is also worth noting that over the last one hundred years or so, doctors have been prominent in the euthanasia debates in the UK, both in favour of and against the intervention. In the 1930s, the Voluntary Euthanasia Legislation Society was led by physicians, but the House of Lords bill to legalise euthanasia was defeated in 1936 after the intervention of two medical peers (Emanuel, 1994). More recently, there have been other attempts to change the law in the UK, both in the House of Lords (House of Lords, 1994; House of Lords, 2005b; Rough and Sutherland, 2020), and the House of Commons, most recently in 2015 (Rough and Sutherland, 2020). All these Private Members Bills have been in relation to assisted suicide, rather than active voluntary euthanasia. In the House of Lords, these included the Assisted Dying for Terminally

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[12] R v Cox [1992] 12 BMLR 38.

Ill [1] tabled by Lord Joffe in 2004 and two Assisted Dying Bills tabled by Lord Falconer in 2014 and 2020 (House of Lords, 2020). In 2015 the House of Commons debated the Assisted Dying (No 2) Bill, which had been tabled by the Wolverhampton SW MP, Rob Morris. This was defeated at division by 330 votes to 118, the members having been instructed that they should vote with their own consciences (Rough and Sutherland, 2020). All the Bills aimed to enable competent adults who were terminally to be allowed assistance with ending their life if they requested it, although they differed slightly through amendments. The arguments for and against these bills were outlined clearly in the debate pack prepared for those attending a debate on the issue to be held on 23 January 2020 in Westminster Hall and opened by Christine Jardine MP (Rough and Sutherland, 2020). They are considered in detail below.

There have also been a number of attempts by individuals to obtain judicial review of the Suicide Act 1961 to allow them to have assistance in suicide, using the argument that the 1961 Act is incompatible with Article 8 of the European Convention on Human Rights (ECHR) [13] (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018; Rough and Sutherland, 2020). These will be considered in more detail in the next section. With this background in mind, it is appropriate to review the arguments that have been put forward in support of, or opposition to a change in the law.

4.5 Euthanasia Arguments

In its simplest terms, the euthanasia debate revolves around two contrasting beliefs, on the one hand, the right of people to make autonomous decisions about their lives and on the other, that it is wrong for one person to kill another (the sanctity of life) (Herring, 2018). This may seem to be somewhat simplified, and a number of other supporting arguments have been deployed by the proponents and opponents of attempts to change the law in the UK (Care not Killing, 2017; Dignity in Dying, 2017). The report on the 23rd (2005) British Social Attitudes Survey included an analysis of the answers to the questions about euthanasia. In

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[13] The ECHR is an international human rights treaty signed by the 47 members of the Council of Europe in 1959. It ensures a legal commitment to each of the articles in each country. Of relevance to the legal challenges on assisted dying are:
Article 2: Right to life
Article 8: Right to privacy and family life

this analysis there was a brief review of these arguments (Clery *et al.*, 2007), which I shall use as a framework to consider the two sets of divergent opinions.

Those in favour of assisted dying rely on three basic arguments, the respect for autonomy, the inconsistency of current law coupled with the fact that it is already happening, and that it would be better regulated if it were legalised (Emanuel, 1994; Schafer, 2013; Dignity in Dying, 2017; Young, 2018). As one commentator remarked: 'One central contention in support of voluntary euthanasia is that respect for persons demands respect for their autonomous choices as long as those choices do not result in harm to others' (Young, 2018: 8). The relationship of the autonomous person to 'others' is the key to how different interpretations of autonomy can be used in the pro- and anti-euthanasia arguments and will be a recurrent theme throughout the thesis. The quotation from Young describes the liberal interpretation of autonomy.

The Human Rights Act (1998) [14] is an often-contested piece of legislation, because of a certain ambiguity concerning Article 2, the right to life, which does not include a right to have that life ended (a right to die). There have been attempts to challenge this in the UK courts over the last 20 years, these include Diane Pretty in 2002 [15], Debbie Purdy in 2009 [16], Tony Nicklinson in 2014 [17], and others since (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). The argument that was proposed in these cases was that circumstances surrounding individuals' deaths were aspects of those peoples' private lives. Therefore, to restrict how they chose to conduct the end of their life (to have assistance to kill oneself) was an infringement of Article 8 (see below). As an example, it is worth considering Nicklinson in more detail. He was a man suffering from 'locked in syndrome', a condition in which he was

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[14] HRA (1998) was UK legislation that contained the rights originally listed in the ECHR
Article 2: Right to life

1. Everyone's right to life shall be protected by law. No one shall be deprived of his life intentionally save in the execution of a sentence of a court following his conviction of a crime for which the penalty is provided by law.
2. Deprivation of life shall not be regarded as inflicted in contravention of this Article when it results from the use of force which is no more than absolutely necessary:

Article 8: Right to privacy

1. Everyone has the right to respect for his private and family life, his home and his correspondence.
2. There shall be no interference by a public authority with the exercise of this right except such as is in accordance with the law and is necessary in a democratic society in the interests of national security, public safety or the economic well-being of the country, for the prevention of disorder or crime, for the protection of health or morals, or for the protection of the rights and freedoms of others.

[15] R (Pretty) v DPP [2002] 1 A11 ER 1, HL.
[16] R (on the application of Purdy) v DPP [2009] UKHL 45.
[17] R (Nicklinson) v Ministry of Justice; R (AM) v Director of Public Prosecutions [2014] UKSC 38.

conscious but only able to move his eyes, and he could only communicate by blinking. He wished assistance in committing suicide as he felt his quality of life was unacceptable and demeaning. His case went to the Supreme Court, where it was heard by nine Supreme Court justices, who rejected the appeal by a majority of seven to two (Wicks, 2014). There are a few important points that arose from this judgement. Firstly, there were two senior judges who stated that there was an incompatibility between the existing law and Article 8 ECHR, in other words they would have accepted the appeal. Secondly, the judges did all agree that Parliament should be the forum where the issue should be debated with a view to providing the necessary legislation.

To date, these legal challenges to the Suicide Act 1961, have not been successful (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). The contention that it is happening already is based on the fact that it is legitimate to refuse or withdraw life-prolonging treatments and therefore to shorten life and this has been termed passive euthanasia (Clery *et al.*, 2007). The argument is extended to suggest that non-voluntary euthanasia has been legitimised as well, in that withdrawal of clinically assisted nutrition or hydration is allowed in the 'best interests' of patients in a persistent vegetative state, as in the case of Tony Bland (Brazier and Cave, 2016). Because this withdrawal would result in the earlier death of the patient, it is therefore arguably euthanasia (Clery *et al.*, 2007; Brazier and Cave, 2016; Laurie, 2016). The opponents of assisted dying, such as those from palliative medicine disagree with this opinion, citing the clear difference between acts of commission and omission, or killing as opposed to letting die (Saunders, 1959; Saunders, 1992; Doyle *et al.*, 1998; Materstvedt *et al.*, 2003; Saunders, 2003; Finlay *et al.*, 2005; Saunders, 2006).

The arguments against assisted dying can be described as moral, practical, and empirical. The principal moral argument relates to the notion that human life is special and that it is wrong to take it away, this I have described as the sanctity of life and have discussed it in chapter 2. Another, and linked moral view, is that doctors' duties strongly include not killing their patients (Emanuel, 1994; Schafer, 2013; Mullock, 2015; Emanuel *et al.*, 2016; Care not Killing, 2017; Sprung *et al.*, 2018; Young, 2018). This is a long-held view and can be traced back to the Hippocratic Oath (Sokol, 2008).

The two most widely quoted practical concerns are the 'slippery slope' and the need for the protection of vulnerable people. The slippery slope argument suggests that the acceptance of a relatively minor practice would eventually lead to 'acceptance of a much more substantial and less favourable practice' (Potter, 2019: 240). Potter further described two forms of the slippery slope argument, the first 'logical' form was based on the conceptual similarities of the practices and therefore the logical progression of one practice to another. The second form, which he termed 'psychological', was based on an intuition of the inevitable and detrimental erosion of moral boundaries in society following the acceptance and legalisation of assisted dying. In the euthanasia debate, one form of slippery slope would be described in terms of the progression from 'passive euthanasia' (withdrawal of life sustaining treatments', to active voluntary euthanasia and then to non-voluntary and finally involuntary euthanasia. The other argument looks at the inclusion criteria for assisted dying, and their inevitable widening over time. Whilst clear definitions and limits of eligibility for an intervention may have been defined initially, there will be a testing and widening of the limits over time to include criteria that were not originally intended (Finlay *et al.*, 2005; Schafer, 2013; Sprung *et al.*, 2018; Young, 2018). The concern would be that the acceptable criteria for eligibility for assisted dying would slip from patients with terminal malignant disease and unacceptable suffering to those with chronic disease with suffering, to those with chronic disease without suffering and so on. The evidence from countries where assisted dying has been legitimised is somewhat contradictory, with some authors denying that the slippery slope occurs (Smets *et al.*, 2010; Onwuteaka-Philipsen *et al.,* 2012; Chambaere and Bernheim, 2015; Dierickz *et al.,* 2016; Bernheim and Raus, 2017), but others saying that it does (Habgood, 1993; Lerner and Caplan, 2015; Cook, 2020). What is apparent from the Dutch and Belgian commentators just referenced, is that the number of interventions performed has increased, and range of acceptable conditions has also widened in those countries over the last twenty years. Despite this, they conclude that the controls in these countries are adequate.

Protection of the vulnerable, who might feel themselves to be a burden to society, is another practical concern and a communitarian value expressed widely in the palliative care literature (Saunders, 1992; Doyle *et al.*, 1993; Saunders, 1995; Doyle *et al.*, 1998; Saunders, 2003). Saunders wrote: 'I do not think that any legalized 'right to die' can fail to become, for many vulnerable people, a 'duty to die' or at its best the only option offered' (Saunders, 1992: 3). Finally, the palliative medicine community and the hospice movement express practical concerns about the impact a change in the law would have on their own specialty. They are concerned that if euthanasia were to be legalised, they would be expected to be a part of the process. This in turn would have an adverse effect on the public's perception of what the specialty could offer, and therefore their trust in palliative care and its doctors. There is also concern that euthanasia would be seen as an alternative to palliative care and that this would also impact negatively on investment in palliative care services (Association for Palliative Medicine, 1993; Finlay *et al.*, 2005; House of Lords, 2005a).

The empirical arguments against euthanasia are based on clinical observations of patients approaching the end of life (Saunders, 2006). They focus on the following issues. Firstly, that with adequate attention to pain and other distressing symptoms, requests for euthanasia would cease, or at least become very rare, in other words good palliative care obviates the need for it. This in turn would require adequate investment in specialist palliative care services to meet the need. Secondly, people's requests for euthanasia are really cries for help and not actually genuine demands to be killed. Thirdly, even if requests are thought to be genuine at the time, they are rarely persistent, so if the patient is supported through her time of crisis, she will be able to realise a natural death. These claims have been expressed within the palliative medicine community persistently, since Saunders' first rejection of euthanasia in 1959 (Saunders, 1959; Saunders, 1992; Saunders, 1995; Saunders, 2003; Saunders, 2006; Sprung *et al.*, 2018). As I have shown in the previous chapters, palliative medicine's opposition to euthanasia is underpinned by a strong belief in the intrinsic value of human life. This in turn has been heavily influenced by Cicely Saunders and her own Christian faith (Driver, 2014). What is interesting to note is how she described her faith values in her earlier publications expressing opposition to euthanasia (Saunders, 1959; Saunders, 2006), but this was less evident in her later work, when communitarian values were more apparent (Saunders, 1992; Saunders, 1995; Saunders, 2003). In 1995, she wrote that:

> *'The hospice movement in this country has taken a strong stand against the intrusion of the law of this kind into clinical practice … I believe we can and should constantly reiterate that this is the way to respect patients' and families' true needs. Their autonomy must be seen in the context of society as a whole … I will continue to urge people to realize their own importance to the end of life and our commitment to their care and not in any way to hasten death' (Saunders, 1995: 45).*

As well as the importance of living life to its natural end, supported by society and family, Saunders also demonstrates a degree of paternalism in her words. In saying that she understands their 'true needs' and needs to 'urge them to realize their importance,' she implies that she understands her patient better than he does himself. It is clear that in her opinion, life has a special value, and it should be lived to its natural end.

I have described the arguments deployed by both sides of the euthanasia debate. It seems reasonable to ask whether different sections of UK society are concerned about the issue, and if so, what their attitude actually is. I shall attempt to relate the literature to the UK but will include evidence from other jurisdictions where it compliments that from the UK.

4.6 Empirical Data on Desirability of Euthanasia

In this section I review the data on the support for assisted dying as expressed by different members of society, these include the UK 'public', patients with advanced disease and doctors. As assisted dying is illegal in the UK, I have also reviewed the literature on the attitudes of palliative medicine doctors in countries where it has been legitimised.

4.6.1 Public attitudes

'Public Opinion' on social issues is an emotive subject, which is potentially open to bias and misinterpretation both by the press and by campaigning groups. Some public opinion polls are in fact commissioned by organisations that already have a position on the issue. The two most prominent of these organisations, with opposing opinions on assisted dying in the UK, are Dignity in Dying (previously the Voluntary Euthanasia Society), which campaigns for euthanasia (Dignity in Dying, 2017) and Care not Killing, which opposes it (Care not Killing, 2017). To offer an unbiased account, I shall focus on the British Social Attitudes Surveys (BSAS) [18]. The BSAS focus on different issues each year but return to particular ones at intervals. The most recent survey that included euthanasia was published in 2017 and contained data from their 2016 survey (NatCen Social Research, 2017). In their report, they compared the new data with that from six previous surveys on the same subject dating back to 1983. In response to a question about the acceptability of euthanasia for a 'person with an incurable and painful disease, such as dying from cancer', 77% felt that euthanasia would be a reasonable option if the patient had requested it. It was also noted that this level of support had been essentially unchanged over the preceding 30 years (NatCen Social

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[18] The BSAS is an annual survey of social issues and opinions that has been running since 1983. It is conducted by NatCen, who describe themselves as 'Britain's leading centre for independent social research', using random probability sampling of over 3000 adults aged 18 and over. NatCen (2017) *British Social Attitudes*. Available at: http://natcen.ac.uk/our-research/research/british-social-attitudes/ (Accessed: 28/11/2017).

Research, 2017). Support for euthanasia for people with 'chronic diseases and dependency on care' was around 50% and had shown an increase over the preceding decade. Another analysis of data between 1983 and 2012, indicated a drop in the prevalence of religious faith over the same period (Danyliv and O'Neill, 2015). A logistic regression analysis from the 1994 survey (O'Neill *et al.*, 2003) showed strength of religious affiliation was a significant determinant to opposition to euthanasia. Such a conclusion is in keeping with the faith-based interpretation of the sanctity of life that I have already described in chapter 2. It is clear from these results that the majority of (presumably healthy) British people surveyed do support euthanasia. In their conclusion to the 2017 report, the authors stated that:

> *We have seen that across several issues Britain seems to be becoming more socially liberal in its response to these questions of personal autonomy. Even in the past few years there have been marked increases in the acceptance of same-sex relationships and premarital sex; while longer-term there has been a liberalisation of views towards abortions and pornography. We have also found that a significant majority are supportive of transgender people, though this falls when people are asked questions of practical application. Attitudes to euthanasia have remained relatively stable, but support for the most limited form of euthanasia is strong. Taken together these findings do point to a wider societal spread of a socially liberal attitude (NatCen Social Research, 2017: 23).*

This conclusion illustrates the authors' view that British society had moved further towards the liberal egalitarianism as described by Rawls and later commentators (Rawls, 1973; Kymlicka, 2002; Forrester, 2019). Studies based on the European Values Survey (European Values Study, 2017), which explores the social values within most European countries indicated that public acceptance of euthanasia was stronger amongst Western European countries than Eastern, and that the degree of support in the UK ranked 10th out of the 47 countries surveyed (Cohen *et al.*, 2013; Cohen *et al.*, 2014).

One potential criticism of the validity of 'public' surveys is that the people surveyed were, sampled randomly, and therefore presumably mostly healthy. [19] Unless they had had some contact with people who were dying, and understood what could, or could not be achieved in terms of care, they would be viewing death and assisted dying as abstract concepts rather than real events. In other words, the notion of assisted dying might have been viewed in terms of theoretical rights to have control over death, as opposed to people's actual

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[19] In the 23rd BSAS report, 84% respondents reported that they had no disability. Park, A. (2007) *British social attitudes : the 23rd report*. London Thousand Oaks, Calif. : SAGE.

personal care preferences in a particular clinical situation. However, in the 2007 BSAS report, the authors concluded that ‘this balance of support for and opposition to assisted dying cannot be dismissed as uninformed or superficial’ (Clery, McLean and Phillips, 2007: 50).

The preferences of people who were approaching the end of life should give a more accurate indication of the potential uptake of the intervention if some form of assisted dying were to become legal in the UK.

4.6.2 Attitudes of patients

The data on this issue are difficult to interpret for several reasons. They are likely to be most accurate in those countries that have legislation that allows some form of assisted dying (PAS or euthanasia), and therefore the numbers of actual requests, requests granted and those carried out could be compared with deaths overall. While this data would give an idea of the prevalence of requests for and the uptake of the interventions, they would give little insight into the reasons for these requests. In countries such as the UK there are only a few such studies involving retrospective evidence from family members. The other evidence that I include comes from countries where assisted dying is legal.

Two retrospective UK surveys, in which the relatives of deceased patients were asked about their perceptions of the dying person’s views on their impending death, have been analysed (Seale and Addington-Hall, 1994). These surveys took place in 1987 and 1990. 24% were reported to have wished to die earlier than they would naturally, and 3.6% to have specifically asked for euthanasia. Factors influencing a wish for an earlier death included pain and other distressing symptoms and dependency. Clearly these surveys relied on the next of kin’s memories and interpretations of what their dying relative had said, so the data should be viewed with caution. The prevalence of UK ‘suicide tourism’ to Switzerland (Gauthier *et al.*, 2015: 611) is another piece of evidence of a small but persistent demand for assistance to die sooner from the UK population.

Data from the Netherlands and Belgium, countries in which euthanasia has been legal for nearly twenty years, indicate a progressive increase in requests for, and uptake of the intervention in both of these countries (Onwuteaka-Philipsen *et al.*, 2010; Smets *et al.*, 2010; Onwuteaka-Philipsen *et al.*, 2012; Chambaere *et al.*, 2015; Dierickx *et al.*, 2016). In their 2017 annual review, it was reported that euthanasia had accounted for 4.4% of the total number of deaths in the Netherlands that year (Regional Euthanasia Review Committees, 2018). A similar uptake has also been reported in the Flemish part of Belgium (Chambaere *et al.*, 2015), but less so in the French speaking region (Wallonia) (Cohen *et al.*, 2012). These authors concluded that although there was a 'slightly higher' acceptance of euthanasia within the Flemish general population, the French speaking physicians held more negative attitudes towards euthanasia generally, and towards the obligation to report it even when it had been performed. In this study their conclusion was that the discrepancy in the uptake and reporting of euthanasia in Belgium was due to the cultural differences between the physicians of Flanders and those from Wallonia, rather than of the population that they served (Cohen *et al.*, 2012). I shall be exploring the doctors' attitudes towards assisted dying in countries where it is legal later in this chapter.

Overall, the evidence suggests that there is a modest demand for assisted dying in Western Europe amongst the relevant population of patients. However, the professional culture of the doctors was also highlighted in the last reference, and this will be explored in more depth in the next section, in which I will start with the views of British doctors.

4.6.3 UK doctors' attitudes

I have already indicated that doctors have been prominent on both sides of the UK euthanasia debate in the past (Emanuel, 1994). More recently there have been several studies exploring medical attitudes to euthanasia, and other end of life decisions that may influence the survival of the patient. I have described these earlier in the chapter. Most of these studies have been quantitative, using questionnaire data and statistical analysis of that data. In terms of actual practice, two studies showed that doctors were comfortable with withdrawing life prolonging treatments or prescribing drugs that could potentially shorten life, but not with explicitly performing euthanasia (Ward and Tate, 1994; Seale, 2006). Ward's study did however note that if euthanasia were to be legalised, just under half of the doctors said that they would be willing to perform the act. Generally, slightly more UK doctors indicate opposition to euthanasia than support for it (Addington-Hall and Karlsen, 2005; Pasterfield *et al.*, 2006; Lee *et al.*, 2009; McCormack *et al.*, 2012). Two questionnaire studies involving geriatricians alone (Clark *et al.*, 2001) and comparing geriatricians with intensive care physicians (Dickinson *et al.,* 2002) made two conclusions. Although neither specialty supported assisted dying, the opposition was more strongly expressed by the geriatricians than their intensive care colleagues. Secondly, there was less support for active voluntary euthanasia than for physician-assisted suicide.

Following its 2019 poll on assisted dying (Royal College of Physicians, 2019c), the RCP noted that the proportion of its respondents opposed to assisted dying had dropped and the proportion supporting it had increased. For example, in response to a question on what the RCP's attitude towards a change in the law on assisted dying should be, 43% voted for opposition, 25% for neutrality and 32% to support it. Based on this, the RCP changed its own stance on the issue to one of neutrality (Royal College of Physicians, 2019a). I will discuss the implications of this survey in more detail later in the chapter.

Perhaps the most influential study of UK doctors' attitudes to euthanasia and PAS was Seale's postal survey of medical practitioners in 2007/8. The results were reported in three publications and it is worth considering them in some detail as they form the quantitative benchmark for understanding UK physicians' attitudes to assisted dying (Seale, 2009b; Seale, 2009a; Seale, 2010). Using a commercially available database he sent questionnaires to 8857 randomly selected UK doctors of various specialties, he received replies from 3733, a response rate of 42%, and this formed his dataset. As well as collecting data on specialty, ethnicity, and religious faith, he also included the same questions that had been used in the 2005 BSAS on assisted dying. The report in this had been published in 2007 (Clery *et al.*, 2007), so that a direct comparison with public opinion could be made. Two notional patients were described: a person with an incurable painful illness from which she would die (to capture the cancer death) and another with an incurable and painful illness from which she would not die (a distressing chronic disease). For each scenario, the question asked was whether euthanasia or PAS should be allowed if it were to be requested by that person. Overall, more doctors were opposed to either euthanasia or PAS than in favour of the interventions. This was in direct contrast to the public view when they were asked the same questions (Clery *et al.*, 2007). For instance, 82% of the public said that they would support euthanasia for a person with an incurable and painful illness from which she would die, but only 34% of the doctors overall supported the same scenario. Amongst the medical specialties there was also a wide variation. There was most opposition from palliative medicine specialists, 9.1% supported euthanasia in the scenario just described, as opposed to 39% of 'other physicians'. This latter group contained hospital physicians of specialities other than palliative medicine, elderly medicine, and neurology, which had been listed separately. Respiratory medicine doctors would therefore be included amongst the ‘others’. In his analysis of the data, Seale explored the possible underlying reasons for this disparity in attitudes (Seale, 2009b; Seale, 2010). He noted that palliative medicine specialists were significantly more opposed to assisted dying than the other specialties, and also that a strong religious belief was independently associated with the same opinion (Seale, 2009b). He also noted that palliative medicine specialists were more likely to be Christian, religious and ‘white’ (Seale, 2010). As well as this, he concluded that palliative medicine specialists, doctors with strong religious faith and doctors who opposed euthanasia were less likely to report that they had taken decisions that might shorten life, in other words, denying intent to do so (Seale, 2009a; Seale, 2010). These studies give some limited insight into the differences in attitudes towards the shortening of life between palliative medicine specialists and other physicians, but not much depth. Although the strength of Christian religious faith (and other faiths, such as Judaism and Islam) appears to be of importance, it is unlikely to be the only relevant factor. Questionnaires will only give answers to the specific questions asked. Other than religion, the social structures that might influence such opinions were not and could not be explored. Such influences would be more sensitively studied by a qualitative methodology.

There is a relative paucity of qualitative literature on doctors’ attitudes to assisted dying. After the House of Lords rejected of the Joffe Bill (House of Lords, 2005a), one of its recommendations was that further research should be done to explore health professionals’ views about assisted dying. In the wake of this, a qualitative study of thirteen inner-London GPs views was undertaken, using semi-structured interviews and thematic analysis of the transcripts (Hussain and White, 2009). Attitudes were quite variable. Some felt that assisted dying was fundamentally wrong because of their faith beliefs or that there were not adequate safeguards to protect the vulnerable. Others, who had witnessed patients’ suffering, were tentatively supportive of assisted dying as an option for those patients. Three themes emerged which were thought to influence the GPs’ opinions. These were previous experience (of suffering patients), societal values and the influence of powerful others such as religious leaders. In this study, it was apparent that the doctors were balancing contrasting values in the process of forming of their opinions.

4.6.4 Palliative medicine doctors in countries with assisted dying

It has already been suggested that freedom of personal choice is a central feature of liberal egalitarian societies (Kymlicka, 2002; Wolterstorff, 2012; Gaus *et al.*, 2018; Forrester, 2019). As an indicator of such choice, there is also evidence that in Western European countries there is more public support for assisted dying than there is further east in Europe (Cohen *et al.*, 2013; Cohen *et al.*, 2014). It is not entirely surprising therefore, that in some jurisdictions in Western Europe, assisted dying has been legitimised in some form, or at least tolerated in those countries (Bosshard *et al.*, 2008). Similar developments are taking place in Canada, some USA states and in Australia (Delbeke, 2011; Gerson *et al.*, 2020). In view of UK palliative medicine's opposition to assisted dying, it is reasonable to explore how the two approaches have integrated in countries where it has been legitimised.

Three recent articles reported palliative medicine professionals' attitudes in countries with a more liberal attitude towards assisted dying, namely Australia, Switzerland, and Canada. In the Swiss study, the respondents described the conflict that they experienced between their own palliative care principles and the patient's contrasting autonomous wishes (Gamondi *et al.*, 2019). They stated that they accepted being involved in the decision-making process, but that they were uneasy about prescribing the drugs. In some respects, their values were in line with those expressed in the UK palliative literature (Doyle *et al.*, 1998; Cherny *et al.*, 2015). The apparent difference between their attitudes and those of the UK doctors was that they wished for closer collaboration with the providers of assisted suicide in that country rather than separation from any such service. The Australian study was conceptualised in terms of different perceptions of the nature of a 'good death' (Blaschke *et al.*, 2019). Whilst most participants (10/16) viewed this as being about respecting autonomy and personal choice (in other words in support of assisted dying, if that was the patient's wish), the alternative view was of the inherent value of living and dying naturally. The authors summarised the position as: 'While the perspectives discerned two irreducible positions, both were interleaved with common consideration and shared commitment to reducing suffering and facilitating best possible dying experiences for patients in their care' (Blaschke *et al.*, 2019: 565). In the Canadian study 19 palliative care physicians from Quebec were interviewed (Bélanger *et al.*, 1919). The analysis demonstrated the conflict that they all felt between respecting their patients' autonomous wishes and their own palliative values, which encouraged them to help and accompany the patients towards a peaceful death.

In a systematic review, Gerson (2020) explored this relationship and found differences between the different countries or states. The most integrated system was found in Belgium, where both elements had been supported in the 2002 legislation and palliative care and assisted dying were viewed as being part of the same service (Dierickx *et al.*, 2016; Bernheim and Raus, 2017; Gerson *et al.*, 2020). In contrast, in Switzerland, where assisted suicide had been tolerated and subsequently legitimised independently of medical services, palliative medical attitudes were much less supportive (Bittel *et al.*, 2002; Gamondi *et al.*, 2019). In the USA studies quoted, most respondents were not medical (chaplains, nurses, or social workers) and their responses ranged between cooperation, ambivalence and opposition. It seems, therefore that the jurisdictions that propose a joint development of palliative and assisted dying services achieve a more integrated system than those who do not. What is apparent from these studies is the doctors' awareness of two conflicting value systems underlying their wish to provide the most appropriate and sensitive care for their patients, culminating in a good death. The question that this then raises is whether such care could ever include bringing forward that death.

4.6.5 Summary

I have shown that from their perspective as members of British society, most of the public who were surveyed supported the notion of assisted dying under certain circumstances. This is written with several caveats. Firstly, there are assumptions about the representativeness of the chosen participants within the whole population. Secondly, it raises the question about what relevant knowledge and experience are needed and who is best placed to make such judgements? It is evident that doctors, lawyers, theologians, philosophers, politicians, and ethicists cannot agree on the morality of assisted dying. Despite these concerns, the public have consistently supported a change in the law on assisted dying for the last 30 years. The data from patients suggest that there would be a small number of people, who would prefer to have their life ended rather than continue with their suffering. The attitudes of doctors are easier to summarise, but less easy to interpret, due to the paucity of qualitative data. The data suggest that palliative physicians are more opposed to assisted dying than other physicians, and that neither group approaches the degree of support expressed by the public. In the final section of this chapter, I will aim to delve into the organisations that represent and train the members of the two specialties to explore their potential influence on the how the doctors form their opinions about the subject.

4.7 The Specialties and Assisted Dying

4.7.1 Respiratory medicine, the RCP and assisted dying

Neither the specialty of respiratory medicine, not its specialist society, the British Thoracic Society (BTS) have expressed specific opinions on medical ethics or assisted dying, although the curriculum for respiratory medicine does contain the following learning objectives, amongst others:

- Demonstrates knowledge of the principles of medical ethics
- Shows willingness to seek the opinion of others when making decisions about resuscitation status, and withdrawing or withholding treatment (Joint Royal Colleges of Physicians Training Board, 2020b)

Compared with the attention that is given to ethical theory in the palliative medicine curriculum (Joint Royal Colleges of Physicians Training Board, 2020a), respiratory medicine appears to place less importance on this than palliative medicine. This could be interpreted as that by adopting a biomedical approach to disease, good respiratory medical practice is relatively value-free. Therefore, an over-reliance on ethical deliberation is not necessary. The absence of any reference to assisted dying in the respiratory medicine curriculum may indicate the specialty's wish to distance itself from the debate because it is a societal problem rather than a medical one, or because they do not perceive it to be a relevant in their daily clinical practice. This is interesting as some of the recent test cases have involved patients with respiratory failure who were on ventilatory support and may therefore have had clinical input from respiratory physicians (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018).

Unlike the BTS, the RCP has addressed assisted dying in recent decades. The Committee on Ethical Issues in Medicine (CEIM) was initiated in 1985 at the RCP. Its initial remit was largely as a central reference point for hospital research ethics committees, but its scope has widened over time to include end of life issues and assisted dying (Royal College of Physicians, 1985). An early report from this committee looked at the issue of the medical management of terminal illness (Royal College of Physicians, 1993). In their position statement they said that the RCP's role was to consider the pragmatic and ethical aspects as applied to medical practice. They noted that whilst preservation of life is generally assumed to be a doctor's role, at the end of life, relief of suffering may become more relevant. In relation to this, they also acknowledged the doctrine of double effect. They said that it was important to understand the patient's own wishes and they acknowledged that society's attitude was moving towards respecting individual autonomy over professionals' opinions. They concluded that doctors 'should have the right to practice in accordance with their own conscience, but with due awareness of how the law stands at present. The widespread practice of euthanasia would have an adverse effect on the public perception of doctors and of their role in society.' (Royal College of Physicians, 1993: 2). In an editorial written in 2008, the Chairman of the CEIM noted that the RCP had adopted a neutral position for the Assisted Dying for the Terminally Ill Bill (2005), but then had changed its stance back to one of opposition (J Saunders, 2008). At a later meeting, when discussing how the college should decide on its position in relation to euthanasia, the following statement was made by the College:

> *'The registrar advised that the voice of the fellowship should prevail in such matters and emphasised the RCP's responsibility to respond to consultations on which its views were sought … he noted that while personal moral views were unlikely to change, the RCP's position was not closed' (Royal College of Physicians, 2012).*

This sentiment, that the official college ethical position should be dependent on the views of its constituent fellows, clearly matches the behaviour of a liberal society as has been described by Kymlicka (Kymlicka, 2002). This state of opposition to assisted dying continued until the RCP Council, who are mostly fellows, proposed to hold a new poll in 2019 to assess the prevailing attitudes towards assisted dying. They further proposed that the RCP should adopt a neutral stance unless 60% or more either opposed or actively supported it (Royal College of Physicians, 2019c). This proposal provoked a strong and negative response from the anti-euthanasia lobby, particularly the Association for Palliative Medicine (Association for Palliative Medicine, 2019b). In the poll, three questions were asked:

- What should the RCP's position be on whether or not there should be a change in the law to permit assisted dying?
- Do you support a change in the law to permit assisted dying?

- Regardless of your support for or opposition to change, if the law was changed to permit assisted dying, would you be prepared to participate actively?

In the poll, of the 6885 respondents, 43% voted that the RCP should oppose, 25% to remain neutral and 32% to support a change in the law. The breakdown of responses by specialty, as published by the RCP, is shown in Figure 4.1. The most obvious finding was that palliative medicine's response was markedly different from all the others.

On the basis of this response, the RCP's official position changed to one of neutrality (Royal College of Physicians, 2019a). In a personal communication with all of its fellows, the RCP president concluded that the decision-making process had been completely democratic through its elected council (Goddard, 2019).

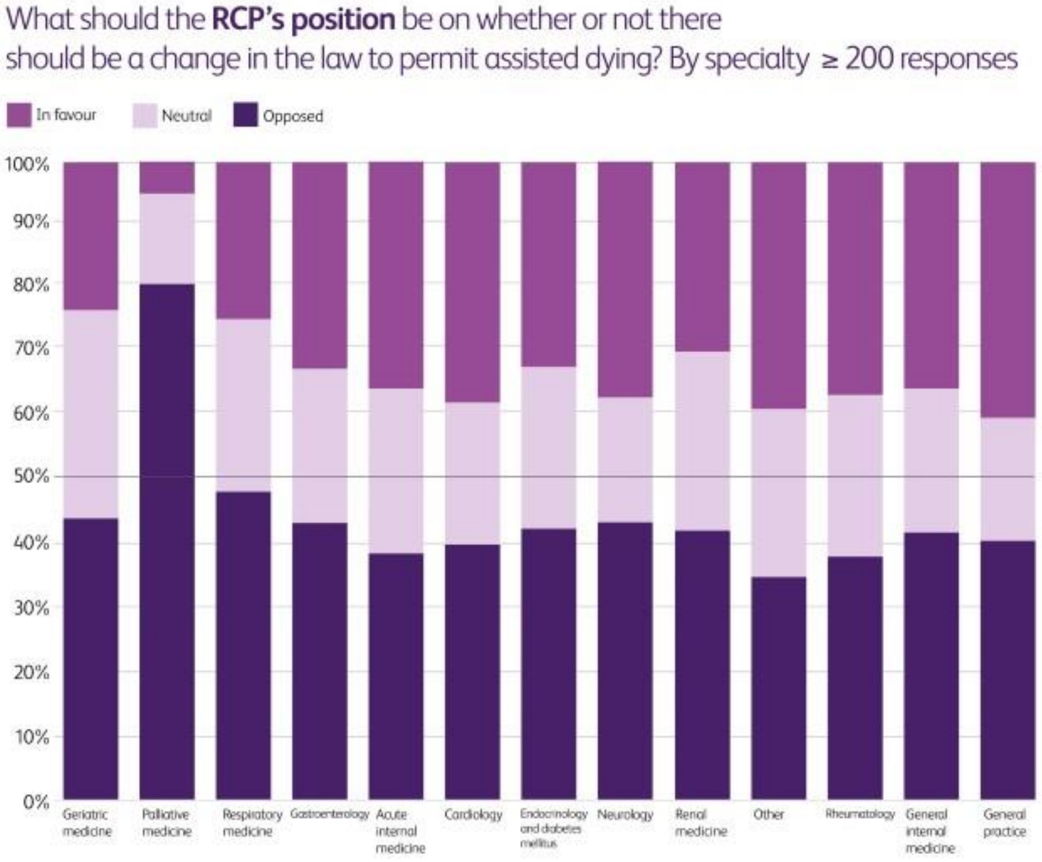

Figure 4.1 Bar chart of responses by specialty in the 2019 RCP survey (Copyright © 2019 Royal College of Physicians. *Reproduced with permission*.)

I suggest that RCP adopts a liberal view on the issue of assisted dying, as it does not seek to push a particular view but accepts that there are differences in opinion. It does however remind its members and fellows to be aware of the law. Another interpretation of the RCP's position is that it wants to distance itself from the assisted dying debate by declaring it an issue for society, not physicians.

4.7.2 The problem of euthanasia

In contrast, the palliative medicine community and its specialist society, the Association for Palliative Medicine (APM) have always opposed assisted dying. The APM last surveyed its membership in 2015, at the time of Lord Falconer's proposed bill. 82% did not think that the law should be amended in line with his bill, 12% supported it and 6% were undecided (Association for Palliative Medicine, 2019a). This opposition can be traced back to Cicely Saunders own views (Saunders, 1959), as this section will demonstrate.

Cicely Saunders' opposition to euthanasia has already been documented (Saunders, 1959; Saunders, 1992; Saunders, 1995; Saunders, 2003). In addition to the publications referenced she was active in other ways, as her biographer has described.

> *Cicely had been an active and vocal opponent of euthanasia long before the hospice opened. Although she did not believe that St Christopher's should be a pressure group, she felt that the staff should stand up and be counted … She debated at the Royal Society of Health and the Cambridge Union, wrote articles, broadcast, was a member of a working party set up by the Church of England Board of Social Responsibility, and, with the Council of St Christopher's, made a submission to the Criminal Law Revision Committee, who were suggesting that there should be an offence of 'mercy killing', distinguishing it from murder (du Boulay and Rankin, 2007: 142).*

It is evident from this quotation that Saunders expected her colleagues at St Christopher's Hospice to share her opinion and express it. In fact, most doctors in the specialty of palliative medicine in this country are opposed to assisted dying (Seale, 2009b; Association for Palliative Medicine, 2019a; Royal College of Physicians, 2019a). In the UK, attempts to change the law have been with respect to physician assisted suicide (PAS) rather than euthanasia. The members of the APM have been active in their opposition whenever there is any attempt to change the law on PAS in this country. They have submitted submissions, both written and oral, to the Select Committee of the House of Lords on Medical Ethics in 1993 and 2005 (House of Lords, 2005a). The APM also provides position statements (against Physician Assisted Suicide) in 2011 and 2019 (Association for Palliative Medicine, 2019a). Members are encouraged to quote from them if approached by members of the press.

A more recent example occurred in the light of the Royal College of Physicians, poll on assisted dying (Royal College of Physicians, 2019c). This proposal provoked a robust response from the APM, which posted web materials to help its members come to an opinion (Association for Palliative Medicine, 2019b). Although purporting to describe both sides of the argument, the APM offered a strongly worded APM position statement (Association for Palliative Medicine, 2017), and in an advisory letter to the trainees, their chair gave the following advice on how to vote:

> *If you have any doubt on this issue, I believe the safest position is opposition, not neutrality. Neutrality will be seen from inside and outside the profession as a shift towards support for legal change, whether in part or in full. That is what happened in 2004 when the RCP briefly adopted neutrality. Given the potential consequences of a change in the law, foreseen or otherwise, I believe opposition to a change in the law on physician assisted suicide (assisted dying) is the only way we can continue to protect the vulnerable individuals for whom we have the privilege to care, and who, ultimately, may stand to lose the most.*
> *With very best wishes, …, Chair of the Trainees' Committee (Association for Palliative Medicine, 2019b).*

It is interesting to note that the RCP survey asked about the RCP's position on whether or not there should be a change in the law to allow assisted dying (without specifying who should do it), with a supplementary question about individual willingness to 'participate actively' (Royal College of Physicians, 2019c). In their introduction in the web materials, the APM reinterpreted the generality of whether the law should change to the specific (and personal) duty of a doctor. They stated: 'This Poll is not about the rights and wrongs of assisted suicide, but whether it should become a new duty for doctors', and 'We urge Members and Fellows to register their vote and opinion, as the RCP's position will have a direct bearing on how Parliament reacts to proposed Bills that come before them.' (Association for Palliative Medicine, 2019b). In response to the survey one member wrote to the APM in their e-Bulletin: 'When we are polled for our views it does feel like we are expected to give a certain answer', and another wrote in the same issue: 'I know at least one palliative medicine Consultant who won't join APM as they feel [the APM's] AS [assisted suicide] stance is so one-sided.' (Association for Palliative Medicine, 2019c). The response was that the organisation (APM) had commentary on both sides of the debate and did not expect a particular answer. In a similar vein, five palliative care consultants wrote anonymously to the British Medical Journal (BMJ) about how they felt that the APM was stifling any free speech on assisted dying.

> *‘The authors of this letter have wanted and tried in different ways to engender an open and fair discussion about this subject with our specialist colleagues … We note that the last time a British palliative doctor wrote about changing his viewpoint on assisted dying, he was subjected to intense criticism and ostracism by his peers’ (British Medical Journal, 2019).*

Another indicator of attitudes to end of life ethics is what is written in textbooks. The Oxford Textbook of Palliative Medicine (OTPM) was first published in 1993 (Doyle *et al.*, 1993) and has now reached its 5th edition (Cherny *et al.*, 2015). Doyle recollected that it had been referred to as ‘The Bible of palliative care’ (Doyle, 2015) and indeed, since the publication of the first issue, the ‘Oxford Textbook’ has become the most important international reference book on the subject of palliative medicine. Interestingly, in each edition there is a chapter on ethical issues, which all include a section on euthanasia. In the earlier editions, the authors adopted the viewpoint of Saunders (Doyle *et al.*, 1993; Doyle *et al.*, 1998). In a position statement from the 1998 edition, the authors stated that:

> *At the end of this century, the signs in Western societies of overt discrimination, of latent racism, of utilitarian insensitivity to vulnerable people, and of tendencies to devalue human beings are too prominent to justify insouciant attitudes regarding the legalization of euthanasia. The law prohibiting euthanasia, even voluntary euthanasia, should be maintained.’ (Roy and MacDonald in: Doyle et al., 1998: 120-1).*

The fourth and fifth editions of the OTPM have had a more international list of contributors and their sections on euthanasia did not offer a judgement on euthanasia. It is noted that although palliative physicians throughout the world tend to reject PAD, there are exceptions, such in Belgium (Matersvedt and Bosshard in: Hanks, 2010).

4.7.3 Summary: the specialties and assisted dying

I have described three different approaches to the issue of assisted dying, by three organisations. The BTS is the simplest to interpret, as it just ignores it. This could be because it does not see it as a clinical problem in respiratory medicine, or that it does not feel it appropriate for a medical specialty to comment on something that exists in a wider world than the specialty. In the previous chapter, I described respiratory medicine’s relationship with the RCP (Turner-Warwick, 1982) and was evident from the responses to the RCP poll (Royal College of Physicians, 2019c; Royal College of Physicians, 2019a) that respiratory medicine was aligned with the other medical specialties, rather than with palliative medicine. I have proposed that the RCP adopted a liberal egalitarian attitude in terms of how it approached assisted dying. It attempted to describe both sides of the argument and it did not seek to influence its membership on how to vote. The proposal to adopt a neutral position could be interpreted as a statement that it should not be medicine's decision to make, but one for society. A position of neutrality does not change the law, so in some ways, it says and does nothing, but maintains the status quo. It does, however, send out a signal of a subtle change in position, from a dominant and powerful medical institution.

The APM, and the specialty it represents, has always been unrepentant in its opposition to assisted dying. I have proposed that at an individual level, most palliative medicine physicians' views are based on a belief in the sanctity of life and a communitarian duty to protect the vulnerable in society from outside interests. Sometimes these views are strengthened by Christian faith, but not always. I have also proposed that at an organisational level, the APM has adopted a communitarian structure, in which the nature of 'the good' has been defined by the organisation. This has been strongly influenced by Cicely Saunders' charismatic leadership during the hospice movement, and it has been maintained by the senior members of the APM, since her retirement.

4.8 Conclusion

I started this thesis with an intention to understand how two groups of physicians in UK medicine could, apparently have developed such different attitudes to assisted dying. I have divided my review of what I feel to be the relevant literature into three chapters.

In the first chapter, 'Setting the Scene', I have explored the important concepts that underpin what it is to be a good doctor. During the course of the chapter, I considered what motivates people to study medicine, which in turn gives an insight into young people's perceptions of a good doctor. This was followed by a review of different interpretations of the doctor-patient encounter and what care and healthcare can mean to different members of the medical profession. At this stage, I showed that there were different approaches towards healthcare between respiratory and palliative physicians. The respiratory physicians express a biomedical, disease centred orientation towards medical practice, in which evidence-based medicine is of particular importance. In contrast, good palliative medicine is characterised by the formation of a caring relationship with the patient and family, with close attention to the patient's lived experience of suffering and a focus on the physical, emotional, social, and spiritual aspects of her illness (holistic care). In my review of the training curricula of the two specialties, it became apparent that medical ethics, both in theory and practice formed a larger component of the curriculum of palliative medicine than respiratory medicine. In contrast, the respiratory curriculum highlights the importance of a biomedical approach to illness, the use if medical technologies and the importance of scientific research.

After providing this background, in the second chapter I reviewed the development of the two specialties. Respiratory medicine, in adopting a disease centred approach, arose as one of the first medical specialties in the RCP. Their physicians developed from poorly respected doctors managing TB in sanatoria, to academic physicians at the forefront of clinical trials and evidence-based medicine. Palliative medicine arose outside the NHS under the charismatic leadership of Cicely Saunders. She herself was a committed Christian, and the specialty still has a disproportionate number of Christians in its workforce today. Saunders' practice was based on a mixture of Christian and communitarian values and holistic care, but with a scientific approach towards symptom control. This summary further illustrates the differences in approach between the two specialties.

In this final literature review chapter, I have examined end of life care with a particular reference to interventions which may actually shorten life. I have discussed the legal interpretations of these and illustrated the importance of the relationship between the law and medical practice. The judgement in the Nicklinson case illustrated the Supreme Court's attitude to the issue, namely that it should be decided in Parliament. The review of assisted dying provided an important background to the final part of this chapter, which was an exploration of the professional bodies and their role in the assisted dying debate. I have illustrated the different approaches of the RCP and the APM, both in terms of their attitude towards the intervention in general, but also in how they did or did not attempt to influence their membership in the recent RCP poll on assisted dying. I suggested that whilst the RCP exhibited a liberal egalitarian attitude towards its members, the APM was essentially displaying a communitarian approach.

In this thesis, my intention is to explore and understand the differences in attitudes towards assisted dying between the members of the two specialties. The evidence that I have just summarised gives some insight into the issues, but not much depth. To obtain such depth it is necessary to obtain empirical data from members of the two specialties. The next chapter addresses how this was achieved.

Chapter 5. Methodology

It was during my transition from specialising in respiratory medicine to palliative medicine that I observed what I thought were differences in the values of the doctors in those two specialties, and this perplexed me. In retrospect, I have realised that my concerns had been triggered by the challenge to my own values, which were different from those of my new palliative colleagues. I have experienced a similar cultural turmoil in my attempted transition from medical practitioner to social scientist during this research project. In the two preceding chapters, I have shown that the two specialties have evolved through different processes, and that they each express some differences in their interpretations of what constitutes good medicine. It is also evident that as physicians working in the UK, all of these doctors also shared many common values. In this thesis, I am exploring the complex web of social structures that underlie the values and beliefs that these doctors express. This chapter outlines how I proposed to address the issue.

Firstly, I shall describe my own position as a doctor with his own views and values, which were challenged when I changed specialty, as this sets the context of the *research questions* that I subsequently developed.

Secondly, I shall show how I faced a second challenge in my approach to answering the research questions. My background in medicine had taught me one approach to seeking knowledge, which I subsequently discovered was not appropriate for the questions I was asking. In approaching it from a social science perspective, I had to adopt a different *methodology*, which was to be qualitative rather than quantitative, as I had originally intended.

Thirdly, I shall outline the actual *research method* that I have used. I performed semi-structured and in-depth interviews of members of the two specialties. I will also address the issues of ethical approval for the study and informed consent by the research participants.

Fourthly, I will describe and justify the way in which I have *analysed the transcribed data*. I will show why I considered that thematic analysis was the most appropriate means of interpreting what the participants were saying to me.

Finally, in my *personal reflection*, I shall examine the validity of the whole process. I will consider my own role in generating the conclusions of the study. This includes the interview process and the interpretation. I will show that reflexivity is a vital part of the research project.

5.1 Research Questions

After graduation, I undertook general medical training and passed the MRCP examination. This is the required qualification for entry into higher specialist training (HST) for any physicianly specialty. My chosen discipline was respiratory medicine. On the completion of my HST in general and respiratory medicine, I took up a consultant physician post in these specialties in 1984. At this time, palliative medicine had not been recognised as a training specialty by the RCP, but because a substantial part of my workload was with patients with advanced disease and with those who were dying, I developed a particular interest in that area of practice. Some years later, with the recognition of palliative medicine as a specialty, I obtained specialist registration in that specialty as well, and started working in a hospice as a palliative medicine physician, alongside my respiratory medical hospital duties. The point of this description is to explain how, although I had been through the formal respiratory medical higher training and adopted its values, I was also accredited in palliative medicine without experiencing its formal training programme, so I missed assimilating some of its culture. Since obtaining MRCP and entering higher training, I spent considerably more time in the company of respiratory trainees and consultants than their palliative counterparts, whom I only encountered in the later years. Indeed, it was only on my election to the Association for Palliative Medicine (APM) executive committee in the early 2000s that I had discovered the attitude of palliative medicine as a community towards assisted dying (Association for Palliative Medicine, 2017). Until then I had not thought much about the issue, and my surprise at the intensity of the APM's coordinated opposition to assisted dying was the initial stimulus for this project.

The research project started with an intention of exploring the two groups of doctors' views about euthanasia and physician-assisted suicide specifically, hence its original title:

A qualitative exploration of the attitudes towards assisted dying expressed by respiratory and palliative medicine physicians, and the influence of their professional organisations.

However, during my initial literature review, and following discussions with my supervisors, I decided to widen scope to look at attitudes towards ‘good medical practice’ as well. With this in mind, my revised research questions were as listed below.

1. What are the differences in opinions expressed by respiratory and palliative medicine physicians about good medical practice and assisted dying, and is it possible to conceptualise them?
2. What are the influences that determine these opinions?
3. What are the relationships between the professional organisations and their members with reference to the assisted dying debate?

5.2 Methodology

When I planned this research, I identified that I wanted to describe and, if possible, explain doctors’ moral views on certain topics. I also wanted to explain any differences, if I found them, between the two specialties and demonstrate whether they were truly different. As a doctor myself, I had formed an idea of how I might approach the problem, and the solution seemed straightforward. I had a theory that palliative medicine doctors had different views on some aspects of medical morality from those in respiratory medicine, and I wanted to ‘prove it’. My initial plan was that I would review the existing evidence, such as it was, and from it, I would construct a theory and design a detailed questionnaire to explore the doctors’ views and the reasons for them. I would then perform statistical analysis of the results of the questionnaire using the Statistical Package for the Social Services (SPSS), which after all, was designed for social science research (Cramer, 1998). This would then ‘prove’, or ‘disprove’ my theory. It seemed so simple that I wondered whether it would contain enough to constitute a PhD thesis. My own initial prejudice towards quantitative methods, and away from qualitative research, was characteristic of that of a member of the medical community. Many doctors do not think about or understand ideas about the philosophical basis of knowledge (Marshall, 1996), and focus on facts, tending to ignore the notion of social construction. Medical (quantitative) research is seen as scientific (Sassower and Grodin, 1987), whilst qualitative is seen as unscientific (Mays and Pope, 2000; Daly and Lumley, 2007), as well as subjective and lacking in factual grounding (Malterud, 2001). There are also concerns about the reproducibility and generalisability of qualitative research in healthcare (Sharp, 1998; Cutcliffe and McKenna, 1999; Gardner *et al.*, 1999) and all these concepts are important to members of the medical profession. It was with this background that I started my journey into social sciences' research. What became evident to me quite quickly was that the philosophical basis of reality in the world (ontology), and how it should be researched (epistemology), were of much more concern to social scientists than to medical scientists (Alasuutari *et al.*, 2008; Bryman, 2016). Medical research is largely based on randomised controlled trials (RCT), translational research and analysis of observational studies and case reports (Reiss and Ankeny, 2016). All of these are based on the assumption that there are objective facts (about diseases and treatments, or whatever is the object of study), which can be measured, and their value assessed by statistical analysis (Sassower and Grodin, 1987), in other words, a quantitative methodology. This type of approach has also been used in social research, and was first described as positivism by Comte in the nineteenth century (Epstein, 2018).

An alternative approach is that social reality is a phenomenon involving the interaction between the people (actors) and structures (such as laws or other societal norms) that have been developed by these actors over time. These structures are under constant evolution under the influence of the actors, and include, for instance, the legal, social and health organisations within societies. This ontology is known as constructionism (Mason, 2002; Bryman, 2016). To gain an understanding of such a world, it is necessary to explore its meaning to the actors experiencing and influencing it, and this epistemology is known as interpretivism (Green, 2004; Bryman, 2016). The way to access such data is to listen to the actors' experiences in some way, and this is a qualitative methodology.

In simple terms, it is apparent that there are two broad approaches to social science research, dependent on the ontological assumptions about the nature of reality and the epistemological assumptions about how it should be investigated (Alasuutari *et al.*, 2008; Hammersley, 2008; Bryman, 2016). This, apparently binary separation that leads to quantitative and qualitative methodologies, has been evident in social sciences' literature over several years (Grix, 2002; Hay, 2002; Alasuutari *et al.*, 2008; Bryman, 2016). A review of the history of social research methods indicates that the relative popularity of quantitative and qualitative methodologies has waxed and waned over the last century (Alastalo, 2008). During the first half of the twentieth century, survey research was dominant, and it evolved from merely collecting facts to formulating theories and then testing them through statistical analysis. Similarly, there was a progression in the sophistication of that statistical analysis, in parallel with the evolution of computing technologies.

The history of qualitative research, however, is less well documented. Although Weber was thought to have been instrumental the development of the Chicago School, such a connection has been disproved, as his publications on the matter were not translated into English until 1949 (Weber, 1969; Platt, 1985). The Chicago School has been credited with the development of the case study and with the development of qualitative methodology in general in the USA (Alastalo, 2008). However, it was with the publications of Glaser and Strauss that textbooks on qualitative methods began to appear (Glaser and Strauss, 1965; Glaser and Strauss, 1967; Glaser and Strauss, 1968). The 1970s marked the beginning of the so-called ‘paradigm wars’. These were philosophical arguments about the two conflicting clusters of beliefs about the conduct of research, as I have described above (Bryman, 2008).

At this stage of my social science education, it seemed to me that the literature indicated that there were two opposing paradigms that existed in social research, and that the two should not mix. Grix illustrated the incompatibility of these two approaches using the example of studying social capital. He wrote that ‘the interrelationship between the core concepts of social science (ontology, epistemology, methodology, methods and sources) ... this directional and logical relationship needs to be understood, if students – and academics – are to engage in constructive dialogue and criticism of each-others’ work’ (Grix, 2002: 175).

As I reviewed the literature on my own chosen topic (doctors’ attitudes to assisted dying), I was struck by my observation that most of the relevant key studies were in fact quantitative (Seale, 2009c; Seale, 2009b; Seale, 2009a). As I shall justify later, my view of the nature of medical ethical values is that they are socially constructed, so how could they be understood through a quantitative methodology? It is tempting to speculate that whilst quantitative methods might be appropriate for the exploration of trends in whole communities, the deeper exploration of an individual’s values would be better achieved using qualitative methodology. Put another way, the quantification of a fact, such as that palliative care physicians are more religious than other physicians (Seale, 2010), is different from understanding why and how this happens. My intuition that there is a blurring of the boundaries between the two paradigms, is expressed more succinctly by Braun and Clarke, when writing about the potential applications of thematic analysis, the analytic method that I eventually chose to use (Braun and Clarke, 2006; Clarke and Braun, 2017).

> *As we have argued, thematic analysis can be conducted within both realist/essentialist and constructionist paradigms, although the outcome and focus will be different for each. The question of epistemology is usually determined when a research project is being conceptualized, although epistemology may also raise its head again during analysis, when the research focus may shift to an interest in different aspects of the data. The research epistemology guides what you can say about your data, and informs how you theorize meaning. For instance, with an essentialist/realist approach, you can theorize motivations, experience, and meaning in a straightforward way, because a simple, largely unidirectional relationship is assumed between meaning and experience and language (language reflects and enables us to articulate meaning and experience). In contrast, from a constructionist perspective, meaning and experience are socially produced and reproduced, rather than inhering within individuals (Braun and Clarke, 2006: 85).*

After I had assimilated the history and theories of the conduct of social research, I re-considered my research questions with a view to a more sensitive way of addressing them. In the following paragraphs, I will justify my choice of a qualitative methodology and the actual research methods used.

The research was an enquiry into the values that physicians hold about ethical medical practice. The choice of research methods was based on some assumptions about the underlying ontological nature of medical opinions, and therefore the epistemological position needed to adopt to provide an understanding of them. There is some considerable debate about the respective contributions of biomedicine and social constructionism towards medical knowledge about the nature of diseases and their treatment (Bird *et al.*, 2013; Nettleton, 2013). For the most part, doctors adopt a biomedical view of diseases and the efficacy of their treatments, which can be tested and shown to be effective by statistical methods (Sassower and Grodin, 1987). In other words, they adopt an objectivist approach to disease and illness. However, opinions on medical ethical issues, such as the nature of the doctor/patient relationship, the withdrawal of life sustaining treatments at the end of life and the morality of assisted dying, are formed under the influence of the social world and the people living in it. The morality of medical opinion and practice is largely socially constructed, and will change over time, and reflect the values of the members of that society at that time. The influences that help shape doctors' values are likely to start in childhood in the family and continue through school and university. Undergraduate training in medical ethics has been mandatory in medical schools since the 1990s, and a UK core curriculum for medical ethics and law was first published in 1998 (General Medical Council, 1993; Ashcroft *et al.*, 1998; Doyal and Gillon, 1998). Postgraduate training adds the prevailing values of the medical establishment, as is embodied in the General Medical Council guidance on good medical practice (General Medical Council, 2013). In these ways, the GMC attempts to ensure a consistency in the opinions that doctors express. In the clinical working environment, the opinions of peers, both medical and non-medical will be relevant, as well as the values of the employing organisation, and to some extent the professional societies to which the doctors belong (Royal College of Physicians, 1993; Association for Palliative Medicine, 2019; British Thoracic Society, 2019).

For me to explore the nature of their attitudes and values and the relevance of these potential influences on them, I have assumed that the doctors involved in the study were able to interpret and discuss their own lived environment as they experienced it. This must include both their working lives, as well as their world outside of work. The collection of such data is dependent on an epistemology that allows the researcher to interpret the participants own interpretations of their lived world, a philosophy in which people's understanding of the social world is guided by their experience of it (Bryman, 2016). To access this sort of data, a qualitative methodology is most appropriate. The research data is collected in an exploratory fashion and analysis of it generates an insight and understanding of the relevant issues. in other words, it is inductive (Mason, 2002). In this research, I am seeking to understand and interpret doctors' values as they express them to me. This approach has been described as the '*traveller metaphor*', in which I am the traveller, and my participants are the local inhabitants.

> *"The interview traveller, in line with the original Latin meaning of conversation as 'wandering together with', walks along with the local inhabitants, asking questions and encourages them to tell their own stories of their lived world. The potentialities of meanings in the original stories are differentiated and unfolded through the traveller's interpretations in the narratives he or she brings back to home audiences." (Kvale, 2007: 19-20)*

What is important to note is that although I was in the position of the traveller for the research, I had also been a *local inhabitant* in both lands in which I was travelling. I had started in respiratory medicine, and then moved to palliative medicine. With retirement, I had left both, but a part of me had remained in each. Having lived among my two groups of inhabitants, I already understood some of the customs and values that they held. Following my literature review, I understood much more of the background, so the notion of purely inductive research seemed a bit far-fetched. I was already developing my own ideas, although I could not illustrate them. I shall consider the relationship between theoretical and inductive thematic analysis (Braun and Clarke, 2006) when I review analytic techniques later.

Qualitative research, such as that conducted through in-depth interviews, attempts to 'see through the eyes of the people being studied' (Bryman, 2016: 392). In this way, it should provide a richer description and interpretation of social issues than, for instance, questionnaire-based investigations, which will only give simple answers to the questions that were asked (Mason, 2002; Denzin and Lincoln, 2003; Alasuutari *et al.*, 2008; Berg and Lune, 2016; Silverman, 2016).

There are, however, criticisms of qualitative research, even in the context of understanding social values. The first is that the research represents the researcher's own interpretations of the participant's words and is therefore subjective and susceptible to bias (Daly and Lumley, 2002; Daly and Lumley, 2007; Bryman, 2016). A second, and related concern, is that because of the relatively small sample size that is usually involved, the data may be considered to be anecdotal in nature, and therefore be of questionable validity, and not generalisable. Several commentators have attempted to address these issues. For instance, a hierarchical framework for assessing the quality of qualitative healthcare studies has been proposed (Daly *et al.*, 2007). The four-level scale ranged from 'single case study' (level IV) to 'generalizable studies' (level I). The definition of a 'generalizable study' was described in these terms: 'Sampling focussed by theory and the literature, extended as a result of analysis to capture diversity of experience. Analytic procedures comprehensive and clear. Located in the literature to assess relevance to other settings' (Daly *et al.*, 2007: 46). Apart from the quality of the design, they stressed the importance of the study being consistent with the existing literature. Another author describes 'theoretical generalizations' made from qualitative studies as being different from the 'empirical generalizations' made from quantitative research, but it was stressed that they could still be valid (Sharp, 1998). In a commentary on a GP's qualitative study of her own angina patients' reluctance to engage with cardiologists (Gardner *et al.*, 1999), the strengths and limitations of such work were outlined, and the conclusion was similar to that of Sharp. Green wrote that 'the generalisability of this study does not derive from the representativeness of the sample, but from the concepts … that may well be relevant to other settings' (Green, 1999: 421). In a review of the contents of one volume of the journal Sociology, the notion of *moderatum* generalisation was discussed and it was proposed that it should be incorporated into research design (Payne and Williams, 2005). The characteristic of *moderatum* generalisations is that they are 'first and foremost moderate. They most resemble everyday generalizations of the lifeworld in their nature and scope' (Payne and Williams, 2005: 297). Another response to the generalisability question is that it is attempting to apply quantitative standards to qualitative research, and this is inappropriate, because qualitative studies should be judged by their relevance to the research questions, their honesty and the quality of interpretation (Mason, 2002).

It is evident that researchers in this field are keen to justify the potential for the results of qualitative research to be appropriate for illustrating insights with wider application. The key, they indicate, is in the design and conduct of the research, and I discuss this in more detail in the next part of the chapter.

5.3 Research Design

This is a qualitative study exploring the opinions and values of two groups of physicians. Having decided on a qualitative methodology to explore the research questions, I chose in-depth interviewing as the most appropriate means of accessing my research subjects' experiences and values. The interview is an encounter conducted on an equal basis, whereby the researcher encourages the participant to share her view of the topic in her own words as she believes it to be (Minichiello, 1990; Green, 2004). I had considered other potential sources of such personal information but rejected them for the following reasons. Observational methods, such as ethnography, would have the advantage of allowing me to observe the participants' behaviour, potentially in relevant circumstances, with their patients and other professional colleagues. However, there are reasons why this approach was not appropriate. Issues such as euthanasia are very sensitive and, as will be seen, rarely explored in the doctor-patient interaction, so the likelihood of such a discussion happening at the time I was observing would be very low. Similarly, because of the sensitivity of these issues, the presence of an observer might interfere with, or alter the conduct of that interaction. Thirdly, some of the areas that were discussed in the interviews, such as belief systems, would not be a natural part of the medical interaction. This is because they are usually internal thoughts, rather than externally expressed views. Finally, the need for additional NHS ethical approval and patient consent would not be justified by the added information gained, if such a method were used. The other modality that I considered was group interview. This would have the potential advantage of allowing me to observe interactions between the group members (Green, 2004; Alasuutari *et al.*, 2008) and to obtain more than one opinion at a time. However, as already intimated, attitudes to morally contentious issues such as euthanasia are very sensitive and personal. Although confidentiality would be essential and ensured, some participants might feel inhibited by the presence of their peers, particularly if their opinion were not shared by the majority of the others. I have already shown that some palliative consultants have felt shunned by the palliative medicine community for expressing liberal views towards assisted dying (British Medical Journal, 2019). Having justified my choice of a qualitative study, using in-depth interviews, I shall now describe the practical aspects of the research process.

5.3.1 Participant recruitment

The doctors that I intended to interview belonged to one of two specialties, palliative medicine, and respiratory medicine. I had worked in both specialties in the North of England and had decided to recruit from this geographical area. Both the respiratory and palliative medicine communities in the region are small enough that most physicians in each specialty are acquainted with each other. Although my relationship with my potential participants would be primarily as a researcher, I would also have been a senior colleague of some, a supervisor to a few and a peer to all of them.

I decided to approach the regional specialist societies representing the two disciplines in the North of England. This was for a few reasons. I am a member of both the Northern Region Palliative Care Physicians Group (NRPCPG), representing palliative medicine specialists and the North of England Thoracic Society (NETS), representing respiratory specialists. These organisations fulfil two functions for their members, firstly to act as a focus where the doctors can discuss professional and training issues in general, and secondly as an educational resource, where members make academic presentations, case reviews or review current literature.

At a meeting of each group, I outlined my research, and requested volunteers to allow me to email them with an information sheet and a request for an interview at a time, date, and place to suit them. I felt that knowing the potential participants professionally would improve the research relationship and enable a more honest and in-depth exploration of their values. The other principal reason was of geographical proximity for me to travel to do the interviews within the North of England. From each of the meetings I obtained more than 20 e-mail volunteers for each specialty. There was no reason to suggest that these volunteers were not representative of their specialty overall.

Because the working environments and practices of the two groups of physicians are very different, these may influence the relationships of those doctors with both the patients and families they look after and the other healthcare professionals that they interact with. I shall therefore describe these environments in some detail to give some context to the illustrative quotations that will follow in the data chapters.

Palliative medicine specialists can potentially work in three separate environments, although as individual consultants, most work in only one or two of them (Joint Royal Colleges of Physicians Training Board, 2019a; Health Education England, 2020a). These environments are in community liaison, in hospital liaison and in specialist palliative care inpatient units (hospice or hospital unit). In the community, the patients are ultimately under the care of their general practitioner (GP). Specialist palliative care advice is initially provided by clinical nurse specialists, known as Macmillan Nurses (Macmillan Cancer Support, 2020). If they need a senior medical opinion, the Macmillan Nurses will call in the consultant in palliative medicine to visit the patient at home and then advise on subsequent care. Although their advice is usually heeded, they do not hold the ultimate clinical responsibility, which is in the hands of the GP. Apart from visiting patients in their own homes, much of the consultants' time is spent on education and coordination of services rather than direct patient contact. A similar situation exists in acute hospitals, where the palliative medicine consultants provide tertiary advice on the management of patients under the care of hospital consultants of other disciplines. They are supported by hospital Macmillan Nurses, and will provide education and guidance to them and other healthcare workers in return. The only circumstance where consultants in palliative medicine do actually have direct clinical responsibility for their patients is in hospices or hospital specialist palliative care inpatient units. These are inpatient facilities fulfilling several specific functions. Patients may be admitted directly to them from the community or transferred as inpatients from nearby hospital wards. The purposes of such admissions include end of life care (terminal care), for the management of difficult symptoms, for respite care and for rehabilitation prior to discharge home (Association for Palliative Medicine, 2019; Joint Royal Colleges of Physicians

Training Board, 2019a; Health Education England, 2020a). Some of these units are NHS funded and some originated as voluntary (independent) hospices which the NHS now funds in part (Overy and Tansey, 2013; Clark, 2016). Most palliative care consultants and all the trainees hold NHS contracts, although some of the consultants are employed by independent hospices.

Respiratory medicine is a hospital based mainstream medical specialty, which exists entirely within the NHS. Most of these consultants possess specialist registration in acute medicine as well as respiratory medicine, and part of their workload will usually be in supervising acute medical admissions, who may have non-respiratory problems. All respiratory consultants have the overall clinical responsibility for the care of inpatients with chest diseases on specialist respiratory wards in acute NHS hospitals. The respiratory consultants predominantly work with NHS contracts, with, or without honorary University appointments. Alternatively, academic respiratory physicians may hold formal university appointments with honorary NHS status (Joint Royal Colleges of Physicians Training Board, 2019b; Royal College of Physicians, 2019; Health Education England, 2020b).

As most palliative medicine specialists are women, I recruited relatively more female respiratory consultants than are distributed across the speciality, to try to obtain as close a demographic similarity between the groups as possible. The reason for this was to try to exclude, as much as possible, any gender or age bias in the responses. Other potential determinants of response, such as religiosity, were not obvious prior to interview. All the participants were British or Irish citizens and graduates, one was of South Asian heritage.

5.3.2 Sampling

In general terms, the selection of subjects for qualitative research is quite different from the probability sampling that is appropriate in quantitative studies (Bryman, 2016). The aim of the sampling strategy in a qualitative study is to select individuals appropriate to the research questions being asked and is usually described as purposive sampling (Green, 2004). Within this term, a number of particular approaches have been described (Bryman, 2016), of which three are appropriate to this study. As one of the objects of the study was if possible, to be able to generalise its findings, it was important to obtain as representative a sample of doctors within the two specialties as possible. Initially, I adopted convenience sampling, to develop and test the interview technique before embarking on the main body of interviews. As I will describe later, I performed a preliminary data analysis after each interview and had some idea of the emerging themes. The second stage was to attempt to strengthen the concepts and the third was to test the ideas by choosing potential outliers. To achieve these aims, I also used snowballing and theoretical sampling to obtain the potential range of opinions on the issues that were being discussed (Green, 2004; Bryman, 2016).

In specific terms, I interviewed all the palliative physicians first, because an NRPCPG meeting occurred at the beginning of the year that I was collecting data, so I was able to start recruitment immediately. This meeting was attended by nearly all the local palliative physicians, enabling recruitment from as wider range as possible and therefore reduce the likelihood of bias. I had decided that it would be logistically easier to complete one specialty at a time as I was using an approach that was influenced by grounded theory, and therefore I needed to compare emerging themes as I was choosing the next participant. The only obvious variables that I chose to consider before recruiting the next volunteer were gender and age, although as will be seen later, there were other determinants of the participants' values that became apparent after data analysis. I sampled from as many employing organisations (NHS Trusts or hospices) as possible to widen the range of those environments and reduce possible bias. After I had completed sixteen interviews with palliative physicians and performed a preliminary analysis, I repeated the process with the respiratory doctors. The palliative doctors were interviewed between January and April 2018 and the respiratory physicians between May and August in the same year. The demographic details of the doctors that were interviewed are listed in table 5.1.

There was a preponderance of women in the palliative medicine group, which is in keeping with the gender ratio in that specialty the UK as a whole (Royal College of Physicians, 2019d). The data from the RCP survey relevant to these two specialties is summarised in Table 5.2. Because of this imbalance, and to reduce any purely gender-related bias in the results, I theoretically sampled women if possible, from my pool of respiratory volunteers. In this way, I achieved a 50:50 gender distribution amongst the respiratory physicians that I interviewed. It should also be noted that to address any age-related bias and to be able to interview younger members of each specialty, I interviewed six trainees, four from palliative medicine and two from respiratory medicine. All were in the last year of training and near to obtaining their Certificate of Completion of Training (CCT). Another reason for interviewing doctors across the age spectrum was to explore whether maturity was in any way influential on the strength or certainty of individuals' ethical values. Just under half of the palliative doctors held a postgraduate qualification in general practice (MRCGP) and the remainder in medicine (MRCP). The specialty acknowledges either qualification for higher training, in contrast to respiratory medicine, which only recognises MRCP. More respiratory physicians had completed a higher research degree (doctorate) than those in palliative medicine. This is not mandatory but reflects the respective academic and research aspirations of the members of each specialty. The other difference was a higher prevalence of a relevant religious faith amongst the palliative medicine physicians compared with those specialising in respiratory medicine. This will be discussed later

	Palliative Medicine	**Respiratory Medicine**
Male/Female	5/11	8/8
Age range (years)	31-60	33-60
MRCP	9	16
MRCGP	7	-
Doctorate	4	11
Christian faith expressed		
Active	9	1
Background, still relevant	6	2
Background, not relevant	-	1
None	1	12

Table 5.1: Demographic Details of the Participants
MRCP: Member of the Royal College of Physicians
MRCGP: Member of the Royal College of General Practitioners

The data from the most recent Royal College of Physicians' workforce census (Table 5.2) illustrates three points. Firstly, there was a much higher proportion of women in both consultant and training posts in palliative medicine than there were in respiratory medicine. Such a discrepancy has been evident since the specialty evolved, Secondly, in both specialties the proportion of women in training posts was lower than in the consultant workforce. Thirdly, there were more than twice as many respiratory physicians as palliative medicine specialists overall.

	Female	**Male**
Palliative Medicine		
Consultants	504	159
Higher Trainees	194	34
Respiratory Medicine		
Consultants	452	1004
Higher Trainees	378	387

Table 5.2: RCP Census Data. Numbers of female and male consultant physicians and higher specialty trainees in palliative medicine and respiratory medicine in the Royal College of Physicians 2018-19 census (Royal College of Physicians, 2019d).

5.3.3 The Interview process

In general terms, interviews in social research can be described as structured, semi-structured and unstructured (Alasuutari *et al.*, 2008; Bryman, 2016). The structured interview is commonly used in survey research and is characterised by the interviewer asking exactly the same set of questions to each participant in the same circumstances. The questions are specific as should be the answers, which can be then scored (Bryman, 2016). It is an important tool in quantitative research, but not appropriate for this study, as opinions and values have a uniqueness that cannot be adequately understood in statistical terms. At the other end of the spectrum is the unstructured interview in which the topic is mentioned and the participant encouraged to respond without prompting. This has been likened to a conversation (Burgess, 1990). Between these two extremes lies semi-structured interviewing, which has the advantage of allowing participants to pursue tangential thoughts, if thought appropriate by the researcher, whilst still being under the direction of the topic guide (Mason, 2002; Kvale, 2007; Berg and Lune, 2016).

I prepared for the in-depth, semi-structured interview by writing a topic guide, to be used as an aide-memoire for me during the interview. The topic guide (Appendix X) was based on my own experiences as a consultant physician in both respiratory and palliative medicine, discussions with my supervisors and my understanding of the relevant issues that had arisen during my review of the literature. The conduct of the interview was for me to start with the less contentious issues, so that the participant could relax, and then move on to the more challenging areas. These included attitudes to suicide and euthanasia. As the interviews progressed and I became more confident about the whole process, I used the topic guide less rigidly, to allow the subjects to develop their own lines of thought.

The interviews were conducted at a place of the participants' choosing. This was usually in their workplace office, always in private, with no other people present. I obtained written consent, having previously emailed them an information document describing the project and what would be involved in the interview (Appendix Y), which they were invited to question. I conducted the interview as described above and recorded it digitally. On the same day as the interview, I downloaded the recording to a password-protected file on the university server, ready for transcription. I had already ascribed codes to each of the participants so that the transcribed documents were only identifiable by the code. I transcribed all the interviews myself within three or four days of the interview. For this process I used NVivo 11 Pro software (NVivo, 2018), that the university had provided. This programme was only used for the actual transcription of the recorded interview. It was not used for computer-assisted qualitative data analysis (CAQDAS) (Bryman, 2016). The transcribed interviews were saved as anonymised (coded) Word documents in a password protected file in my account on the university server. The digital recordings were then erased.

5.3.4 Research ethics approval

The project involved interviewing a group of doctors who held substantive appointments working with NHS patients in the North of England. The doctors would be discussing sensitive issues, such as their attitudes to assisted dying, which is currently illegal in the UK. There would be no patient involvement in the study, although the doctors might refer to individual patients and other doctors during the interviews. In the first instance, I completed the University Ethics Form V 2.1. The study did involve 'discussion of sensitive topics', so the project was flagged as requiring further review by the Faculty of Humanities and Social

Sciences Ethics Committee. This required further questions to be answered and a review by a member of that ethics committee. Several logistical questions were asked by the representative of that committee, to which I responded. Ethical approval was granted by the ethics committee on 12th July 2017.

My only personal concern was whether any of the participants might be become upset by discussing morally sensitive issues during the interview. In the event, two of the respiratory doctors, one consultant and one trainee, became slightly tearful when remembering and describing events from their earlier careers. Both were asked if they would prefer to stop the interview, but they both wished to continue, and their distress subsided. After each interview, I had written to the participants to thank them for participating. The great majority replied saying how much they had enjoyed the process and how stimulating they had found it. In addition, the following quotations from the participants' closing responses after the interviews illustrate their feelings about the process.

> *'OK* (laughs) *… I think it's thought provoking, it's right to explore these things.' Rebecca, respiratory*
>
> *'It's quite interesting to reflect on it actually. Because although you hear about it all the time, you pick up on things and you have opinions, you don't often get to articulate them. No, I enjoyed it.' Ryan, respiratory*
>
> *'Well, I found it harder than I thought to answer the questions because there's so much, isn't there. There's so much around it all, it's quite emotional.' Nicole, palliative*
>
> *'It was very good to talk it through and I think what you're doing is very helpful.' Christopher, respiratory*
>
> *'That was really ... I was anxious about doing that beforehand.' Michael, palliative*

They expressed some anxieties beforehand, and mixed emotions during, but a positive overall experience of the completed interview.

5.4 Data Analysis

As a novice to qualitative research, I found the analysis of the transcripts much more challenging than conducting the interviews or even transcribing them. The interpretation of a patient's medical history was a relatively linear process, leading, hopefully to a diagnosis. The interpretation of qualitative interviews was quite different, requiring imagination that medicine would view as inappropriate.

5.4.1 Choice of analytic method

The transcripts of the interviews generated a large volume of fairly unstructured text containing the data. Within this text were three types of responses from the participants. Firstly, there were factual statements, as remembered by the participants, of past events in their lives. Secondly, there were the participants' interpretations of these events and the significance of them. Thirdly, the doctors expressed opinions on theoretical situations and abstract concepts. They were encouraged to explore their own underlying values as part of all three of these responses. My aim in analysing the data would be to try to understand and interpret the participants' own perceptions of the moral world around them. As a doctor in clinical practice, I had developed some skills in interpreting what I thought people were trying to tell me when there were ambiguities, or potentially conflicting courses of action. However, it felt to me that such interpretation was intuitive, rather than being achieved by the application of a theoretical framework. For this research, I needed a more formal framework, both to help me achieve an appropriate standard of interpretation, and for the product of the research to be scientifically credible.

There are several approaches to the qualitative analysis of interview data. Broadly these can be separated into those which arose from a particular epistemological position, and those which are independent of any particular theory (Braun and Clarke, 2006). Examples of the former include conversation analysis, interpretative phenomenological analysis, narrative analysis, and grounded theory. Each of these has its own theoretical framework and a particular way of using the method. Having said that, following the original publication on grounded theory (Glaser and Strauss, 1967), the two authors subsequently developed their theory along different lines, with different attitudes towards the relative importance of concepts or theories (Glaser, 1992; Strauss and Corbin, 1998; Charmaz, 2006; Bryman, 2016). Thematic analysis (TA), on the other hand, is relatively free of theoretical constraints, and this appealed to me as recent convert to social science research. Braun and Clarke wrote that 'Qualitative approaches are incredibly diverse, complex and nuanced … and thematic analysis should be the foundational method for qualitative analysis. It is the first qualitative method of analysis that researchers should learn, as it provides core skills that will be useful for conducting other forms of qualitative analysis' (Braun and Clarke, 2006: 78). I chose TA as my analytic method, although I was influenced by grounded theory in my sampling strategy, as I shall show. Grounded theory has several essential features, of which two were relevant to this study. Firstly, by performing initial coding soon after each interview and before the next, I was able use the preliminary codes to inform the next interview. In the later stages of each group of interviews, it also informed the choice of the next participant through theoretical sampling. The other feature of grounded theory that was relevant in this study was ’saturation of themes’ in determining the number of interviewees for the first group that I interviewed (palliative physicians). At this point, no new or relevant data or themes are emerging, and the themes are relatively well developed. When I was satisfied that no new relevant material was forthcoming, which was after about 14 interviews, I completed two more to be certain, then stopped the process. The next stage was a more detailed analysis of the 16 transcripts by thematic analysis.

5.4.2 Thematic Analysis

The aim of thematic analysis is to produce a layered interpretation of the participants’ statements, which in turn are their own interpretations of the relevant world around them. In the context of this study, this world encompassed ideas such as morally acceptable behaviour, doctors’ duties, patients’ rights, and the value of life. Using thematic analysis, this understanding of the patterns of meaning to the participants is achieved by constructing a hierarchical system of codes or themes, as I will illustrate. What was particularly appealing to me about TA was its flexibility to be able to accommodate both inductive (semantic) and deductive (theoretical) approaches to the identification of themes (Braun and Clarke, 2006). As a doctor, grounded in a deductive approach to research questions, I felt more comfortable constructing my topic guide based on existing evidence on the issues that I was researching. This would allow me to get a broad overall view of attitudes ‘in a theoretical or deductive or ‘top down’ way’ (Braun and Clarke, 2006: 83). It is recognised that such an approach tends to lead to a less rich and more linear description of the data, and I was encouraged to adopt a more semantic approach. Thematic analysis would enable me to try to make this transition.

Within thematic analysis, several analytic tools have been described. These are essentially algorithms, or practical sequential techniques for converting transcribed interviews into the major themes that constitute the conclusion of the study (Attride-Stirling, 2001; Braun and

Clarke, 2006; Thomas, 2006; Gioia *et al.*, 2013). They all describe how the meanings of short sections of text are coagulated into fewer overarching ideas, with increasing abstraction over three or more stages. For instance, Gioia describes 'first order concepts, second order themes and aggregate dimensions' (Gioia *et al.*, 2013: 21). Others adopt graphical notations, such as thematic maps (Braun and Clarke, 2006) or thematic networks (Attride-Stirling, 2001), each with three levels of organisation and abstraction such as basic themes, organising themes and global themes (Attride-Stirling, 2001). At an even more detailed level, techniques are described to help finding themes within the transcribed text, such as repetitions, metaphors and analogies (Ryan and Bernard, 2003; Bryman, 2016).

The first stage of the actual process for me was to become intimately familiar with the transcripts. I initiated this process by transcribing all the recordings of the interviews myself. As I am a slow typist, this was a very valuable process, which involved playing and re-playing sections of speech, to obtain the correct intonation as well as an accurate transcription of the actual words used. I was able to listen to the fine points of the unfolding narrative. The intonations of speech, such as a rise in the pitch at the end of a sentence to indicate a question, are sometimes difficult to capture in the typed text, but having heard it myself, it made my interpretation of it more real. The next stage was for me to read and re-read the text to thoroughly familiarise myself with its content. I made notations in the margins, summarising my interpretation of fragments of the text. I also highlighted word repetitions where they were obvious. For instance, the word 'care' was expressed recurrently by many of the palliative medicine physicians, but almost never by the respiratory consultants. As an example, in the following abstract, the doctor describes the importance of caring for her patients and their families when she was a junior doctor on a surgical attachment.

> *It was actually the impact on families and caring for them. I only did surgery as a house officer at that time so actually it was the pre-op and post op bit… how are they managing, how are they recovering, how are the families managing. The breaking the bad news to them, how you're caring for them. Melissa, palliative*

Such strategies enabled me to develop low-level sub-themes (or codes) which I would eventually group into a smaller number of themes. I was aware fairly early on, that as well as attempting to perform data driven inductive thematic analysis, I was also engaging in theoretical analysis of larger sections of text, which would represent the participant's response to individual questions (Braun and Clarke, 2006). I would use the latter to give me an indication of what the participant was 'trying to say'. For me, it allowed a 'top down' approach of understanding the meaning of longer passages of text, and then linking them to their smaller constituent sub-themes, which could be illustrated by sections of actual text. This illustrates an issue that has been persistent during the research process, namely my ambivalence towards adopting a purely inductive approach, and how I find a theoretical approach more natural.

With this in mind, I shall reflect on my potential influence on the conduct and outcomes of this piece of research.

5.5 Reflexivity and Reflections

In this section, I discuss both the theoretical and practical implications of my own role in the research process and my reflections on this. I shall show that it is important that I acknowledge my personal experience of having worked in the fields of my research subjects, and the impact it could have on the conduct and interpretation of the research.

5.5.1 Reflexivity

> *'Reflexivity is commonly viewed as the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome' (Berger, 2015: 220).*

This description describes the ongoing process that a researcher must engage in during a qualitative research study to limit bias and strengthen the validity of the research. It is particularly relevant to this study as I have been a clinical practitioner in the fields of medicine of both these specialties and prior to the study had already developed my own opinions about the subject matter. There are both technical and emotional aspects to an exploration of one's own position in relation to a study. In their book on the topic, Finlay and Gough describe the more technical aspects of the process, and review the ways in which reflexivity has been defined and used in qualitative research (Finlay and Gough, 2003). These range from 'introspection' through 'inter-subjective' to 'mutual collaboration". Each stage reflects how proactively the researcher is seeking to insert herself into the research process and the data. At its least intrusive, introspection in reflexivity would involve the researcher comparing her own experiences and feelings internally with those of the subject and being aware how this might affect her response to the participants, and her subsequent interpretation of the data. In the context of this study, I had no intention to do more than this, so will not consider the others. I was aiming to be aware of my own experience of, and attitudes towards the issues we were discussing. I had no intention of offering opinions myself or of influencing what the participants actually said.

The other aspect of reflexivity, which is more relevant to my study, relates to the researcher’s own background and experience of the issues that she is exploring. Berger described three potential scenarios and explored the relevance of each to the research process. They were that the researcher shared the experience of the research subjects, that the researcher moved from a position of being an outsider to an insider during the study and thirdly that the researcher had no prior experience of the study area and remained a relative outsider throughout (Berger, 2015). It is clear that the first of these applies to my position in this study. The point that Berger makes about this position is that ‘such familiarity might enable better in-depth understanding of participants’ perception and interpretation of their lived experience in a way that is impossible in the absence of having lived through it … the researcher must remain constantly alert to avoid projecting own experience and use it as the lens to view and understand participants’ experience’ (Berger, 2015: 230). That was my challenge in undertaking this research.

5.5.2 Personal reflection

I have already indicated that I was a consultant physician specialising in respiratory medicine for several years, before changing my specialty to focus predominantly on palliative medicine. The stimulus for me to undertake this research project was my surprise at the vehemence of palliative medicine’s concerns about assisted dying, of which I had not previously been aware. This would suggest that my own value system was more aligned with that of respiratory medicine than palliative. Within the local palliative medicine community, from whom I selected my participants, I was recognised as a ‘late convert’ to the specialty, and it was widely recognised that I still possessed several respiratory attributes in my clinical style. Having said that, I did not offer any explicit views on assisted dying or other moral issues in general. It is evident from the fact that I chose to undertake a PhD on medical ethical issues that I shared that interest with the palliative doctors. Similarly, although I retained some respiratory activity, it was clear that I had in part left that specialty. I was therefore, both inside and outside the two specialties, able to talk their language, and hopefully to understand their values. The critical point was that I should not let these factors bias either the conduct of the interviews or the interpretation of the data.

As I have identified, I have used an 'introspective' approach to the interview process (Finlay and Gough, 2003), so did not offer my own opinions on issues, even when they were different from those being expressed by the participants. As the participants and I were all medical specialists in disciplines in which we had a shared understanding, the technical and communication aspects were not problematic. I could understand the technicalities of the language and was able to 'interpret their lived experience' (Berger, 2015) without much difficulty. Two additional factors helped me to avoid projecting my values on my participants during the interviews. Firstly, I had already spent years undertaking cancer outpatient clinics, in which my role was to listen to people's problems, and to encourage them to talk about their feelings about their illness. Secondly, and in preparation for the clinics described above, I had been trained in person-centred therapeutic techniques (Rogers, 2004), and these have helped the process. As much as possible, I have attempted to reduce my own bias in relation to the interviews and the interpretation. I will consider these issues again in the discussion, after I have presented the data chapters.

5.6 Summary

In this chapter, I have described both the theoretical and practical elements of the research process. I have shown how the idea for the research developed as a consequence of my transition from respiratory medicine to palliative medicine. I have also described my other transition from medical to social science, and the challenges that I have encountered on the way. I have justified my choice of adopting a qualitative methodology to help me explore my research questions. Over the next three chapters, I will present and illustrate the data and outline the themes that I have chosen. These themes are: The Nature of Care (Ch 6), An Interest in Ethics (Ch 7) and Influences (Ch 8).

Chapter 6. The Nature of Care

The physicians practicing respiratory and palliative medicine are predominantly engaged in a healthcare relationship with each of their patients. In this chapter I will explore this encounter through the accounts of the two sets of participants. This will be considered from two perspectives, which are firstly, how they viewed good medical practice and secondly, how they formed their attitudes towards ethically contentious issues at the end of life. In the first half of the chapter, I will be looking at the range of activities that they undertake in their day-to-day clinical practice, and their views on the nature of good care in general. In the second half of the chapter, the focus moves to the end of life and assisted dying. I shall describe and illustrate the participants' views on these areas from four perspectives. These are their own personal values, their perceptions of the duties of a doctor in these circumstances, how they balance the patient's perspective with their own and finally the importance of the law in influencing how they act.

6.1 The Medical Encounter

It is important to point out at this stage, that the differences in approach to the medical encounter that I shall illustrate in the first part of this chapter are characteristic of each specialty. Before entering the specialty, all doctors will have been exposed to similar influences during their undergraduate and junior doctor training.

In the literature review, I outlined the range of activities of the two specialties and described their similarities and differences. The respiratory specialists are primarily concerned with looking after people suffering from chest diseases, from diagnosis through treatment to cure, or disease modification (British Thoracic Society, 2019; Joint Royal Colleges of Physicians Training Board, 2019b; Royal College of Physicians, 2019e). I described how, in these circumstances, a biomedical approach towards the underlying disease process was the initial approach. However, another aspect of their role is to look after their patients with progressive disease, and they may be involved in their end-of-life care, if it takes place in the hospital setting. This, therefore, overlaps with the activities of the palliative medicine physicians, who are principally concerned with the relief of suffering in people whose illness is incurable and progressive (World Health Organization, 1990; Twycross, 2008; Overy and Tansey, 2013; Association for Palliative Medicine, 2019; Joint Royal Colleges of Physicians

Training Board, 2019a). As well as the management of distressing physical and emotional symptoms, they pay particular attention to the social and spiritual components of suffering. Although Cicely Saunders had initially only concerned herself with people dying from cancer, with the evolution of the specialty it now looks to help people earlier in their disease trajectory. However, their approach is still towards people's experiences rather than disease processes as separate entities. In this section, I shall explore what the day-to-day care that each specialty offers means to its doctors in three themes, a day's work, patient centred and what care means.

6.1.1 A day's work

In this first quotation, from a respiratory doctor, Joseph describes the variety of activities that he undertook within his specialty and appealed to him. He viewed his practice as extending from curative disease treatment through to palliative care, as was described in the literature review (Royal College of Physicians, 2019f; Health Education England, 2020b). The impression he gave was of a busy doctor, performing a wide range of activities and employing practical as well communicative skills. The comments are matter of fact and notable is the absence of any reference to self-reflection.

> *Q: ... Is there anything about respiratory itself?*
> *A: For me it's a combination of: acutely unwell/critical illness - acute asthma, pneumonia: people coming in really sick but equally getting them better really quickly. It's got the procedures, which I quite enjoy doing. It's got chronic disease, so it's not narrowing things down too much. And then it's got the cancer, and part of that, the palliative care side of things. So it just has a good mix of everything for me. I guess early on I was quite into the idea of procedures and for a while thought about ITU alongside, doing the respiratory/ITU crossover thing. (Joseph, respiratory)*

The desire to be busy and trying to sort out everyone's problems was a recurrent theme amongst the respiratory physicians, as in the next quotation from Joshua.

> *Yeah, you could give me nothing to do and I'll find something to do. One of the things I do now is sitting in my office, supposed to do paperwork and I'll go to my ward or another ward "Does anybody need a chest physician?" I like to be busy and active and doing stuff … I have a very mixed job, I see myself as a general chest physician, with an interest in pleural disease, but also do COPD [20] and lung cancer as well. (Joshua, respiratory)*

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[20] Chronic obstructive pulmonary disease

Apart from being busy, the respiratory doctors also valued their ability to solve problems as simply as possible and perceived themselves as being useful to the emergency team, as Rebecca indicated in response to a question about what she felt about her specialty.

> *Yeh. I mean there is this whole thing of "I think it." I think it's diagnostics, respiratory docs are always general medics and I think that's really ... you feel useful as a respiratory doctor, people like you, you're a part of ... you're useful to the admissions suite and things. You kind of sort people out. And yet we're very pragmatic, we don't necessarily go chasing things, we recognise when people are frail and stop much more readily that other people sometimes. And then you've also got procedures, bronchoscopies, the week is varied, all those sorts of things. (Rebecca, respiratory)*

She seemed to be describing what she perceived as the respiratory mentality, a feature common to all her colleagues. An important element that she described was her perception of the ability of respiratory physicians to recognise futility [21] and to limit their interventions when they were perceived as inappropriate (Jecker, 1995; Jecker and Schneiderman, 1995; Laurie, 2016).

If there are typical characteristics of the ideal palliative medicine physician’s day, then the next extract illustrates most of them. Jennifer was reflecting on her first attachment to a hospice as a junior doctor, before she had chosen to undergo higher training in palliative medicine. This attachment was formative in her decision to make a career in the specialty.

> *A: I loved it, an incredible change in pace. I think I must have put on about 2 stone because I stopped moving, much more relaxed. But it was a 32 bedded hospice with 2 wards and 2 SHOs, so I had 16 patients to see, which coming from a medical job wasn't very much but now we would struggle to look after 16 patients. Much much more relaxed but much more interesting and challenging. I think being able to learn from the MDT … I learned a lot from those nurses in that first 6 months. They were quite old school/traditional palliative care nurses at BBB. at one stage their chief exec was a nun, Sr NNN, and she was a very dominant person in the hospice at that time. I learned a lot about spiritual care from her - I don't mean in a negative sense - she was very good, and coming from medicine ... it resettled the balance between medicine and the rest of life really, and I actually started seeing the people in context really. I can remember I started that in the August, I can remember by Christmas time driving north and crying for about 4 hours solid ... just letting go of some of the emotion that I'd experienced in that first few months. I can remember one patient in particular who was young and had a horrible sarcoma, who'd had a hind-quarter amputation and was in a lot of pain, and I knew that when I went back she wouldn't be there after Christmas, and I think I'd done a lot ‘cos I was the doctor on the ward. And obviously the consultant was very*

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[21] Treatment which does not offer a reasonable chance of survival or a modicum of medical benefit (Laurie 2016)

> *involved with that lady and I can remember spending a lot of time with her and her dignity, with that horrible ... she was a very dignified person … and how her dignity was preserved in that context, was quite a beautiful thing and that had a big impact on me.*
> *Q: So sadness but also ...*
> *A: Yeah ... I think recognition that this was really what I wanted to do. I felt in touch with it, very much so. I enjoyed the medicine, I enjoyed the symptom management.* (Names) *was the consultant there, so you can imagine I was grilled in pain and symptom management, it was quite scientific in many ways but he enabled the holistic … he didn't necessarily do it himself but he enabled the whole team to do it. He didn't dominate too much with his medicine but I got a good schooling ... (laughs) … in pain and symptom management in that 6 months. (Jennifer, palliative)*

The first of the elements that Jennifer described as of importance was having adequate time and sufficiently few patients that she could attend to all their individual needs to her and their satisfaction. Her repetitive use of the word 'dignity' in relation to the care of a young woman, who had had a particularly disfiguring operation and was dying, demonstrated her desire for her patient to be shown the respect that she felt she deserved as she approached the end of her life. She felt that they had achieved this. Interestingly, dignity was not a word used by the respiratory physicians in relation to their interactions with their patients. The other important elements of the palliative approach that she described were the multi-professional teamwork that underpins holistic care and her consultant's biomedical approach to symptom control.

Both this and the next quotation illustrate that the participants felt that it is important for palliative medicine specialists to have the time and environment that is conducive to developing the therapeutic relationship that is so central to their practice. This resonates with Saunders' own observations about the caring role (Saunders, 2006). Jason described the most attractive part of his job in the following terms.

To be honest, I still like going to see people at home and you pick up so much from the whole setup and who's around and how the house is and how they're coping, and there's something special about being on their home turf as well. But just being able to come in and hear their story and just go through it, try to piece together what you can try to do to help is lovely. It's such basic medicine, isn't it, but so attractive, kind of what your training's about I suppose. There's nothing particularly technical about it and I'm not technical at all, good with my hands or anything. Being to be able to sit down and spend the time and you know people tell you how much they just feel and value being listened to, don't they? It always feels like a great thing to be able to do. I still love that bit best. (Jason, palliative)

The last two extracts illustrate how these physicians value time to form the necessary close relationship with their patients so that they can fulfil their therapeutic role. The other important element of the doctor-patient interaction that Jennifer alluded to was holistic care, and I will consider this in the next section, when I explore the medical encounter in more detail.

6.1.2 Biomedical or holistic

I have already described the biomedical approach to illness as being an approach based on the principle that illness is largely due to specific diseases that follow the rules of natural science, and that their management should be based on treatments assessed by appropriate objective methods (Bird *et al.*, 2013; Reiss and Ankeny, 2016; Scambler, 2018). I have also introduced the concept of holistic care, in which psychological, social, and spiritual influences are acknowledged alongside the biological in the genesis of illness. I will now explore the relative importance that members of the two specialties ascribe to these conceptual frameworks in their approach to their patients. Central to understanding this is to consider the role of communication in the medical interaction.

In the first example, Brian was describing what appealed to him most, and which he thought he was best at in his daily activities as a respiratory physician.

> *A: The bit that I think I'm good at and like, is actually making a decision and making a management plan. It's very much the acute decision making and management plans that I like.*
> *Q: And how would you summarise how you make a decision on a particular patient, what's the process that you go through?*
> *A: For me, the initial assessment side of things, which is the assimilation and the assessment, experience and I'd still have to say that gut feeling and instinct. I think that's a big part of medicine still.*
> *Q: Do you think that it's down to talking, listening and examining, is that what you're saying, more than the blood tests and scans and things?*
> *A: Yes, I think it's the first three bits, it's, most of it is the talking, listening: the history. Examination gives you a bit and then the blood tests and other bits help confirm what you do. I'm usually of the view that by the time I've had a chat to the patient, got the history , I know 90% of what I want to do with them. The rest is helping to confirm it.*
> *(Brian, respiratory)*

He described the conventional approach to ‘clerking’ patients that has been taught to UK doctors for decades, namely the sequence of history, physical examination and then investigations. This is in search of a diagnosis, which would lead to appropriate treatment. The key to this approach is in the communication with the patient, which takes the form of sequential closed and open questions to secure the information, which will enable a diagnosis to be made (Stevens, 1966; Turner-Warwick, 2005; Bynum, 2006). This is achieved through a form of pattern recognition, as well as, as he indicated, 'gut feeling and instinct". This process is central to the biomedical approach. His use of the phrase *'what I want to do with them'* implies a degree of paternalism in his approach as well.

Other elements of biomedicine are sub-specialisation, and evidence-based disease specific treatments, as this next example illustrates. In this case, Rebecca referred to a rare variant within the spectrum of lung disorders known as interstitial lung disease (ILD). She described how a patient with a previously undiagnosed lung condition was given a specific diagnosis, and a treatment based on evidence (Sackett *et al.*, 1996; Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). This was achieved with and the involvement of other specialists with relevant expertise, and she stated how she valued that approach. She also referred to her own expertise in that area of practice based on her familiarity with this rare condition.

> *A: I like the ILD stuff, particularly where I feel like we really make a difference. So sometimes people have been floating around with other people* (doctors in other hospitals) *for years and they sometimes come up a real height: "What can possibly be going on, nobody knows," and you just say: "You've got chronic hypersensitivity pneumonitis, this is what you need to do." And then you have a discussion with them about what that is, and it is a difficult thing for people to get their heads round. "But we've got some literature about it and we've got a plan for you." And that works because the whole system has been set up wonderfully. We try and discuss them at the MDT* [22] (and) *get the right imaging there when we see them. It's about getting some clarity for the patient and in terms of therapy, I think anti-fibrotics work for people with IPF* (idiopathic pulmonary fibrosis)*, and I think I see that all the time. I know other people are dubious but they don't see the number of people that I see. There are loads of people that we are keeping relatively well for a number of years. So it's no doubt that it's making a difference and it's relatively easy to diagnose and deal with, so I think that's a real thing. And the other is the connective tissue diseases, so the ILDs in relation to those. You can make a real difference by actually getting the diagnosis right, getting the rheumatologist in on the picture for them to do really fancy things and then make you look clever, then making a decision about immunosuppression early on. You know, it makes a difference. (Rebecca, respiratory)*

The biomedical, evidence-based approach is deeply ingrained in the thought processes of the respiratory physicians (Sackett *et al.*, 1996; Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). In the following quotation, Joshua described how he undertook a diploma in palliative

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[22] Multidisciplinary team. In this instance, it would be doctors of various specialties, including respiratory physicians, radiologists, pathologists and surgeons. There may also be a respiratory nurse present.

medicine in another part of the country to try to improve his knowledge and clinical skills in that area of his practice. He described how he was ultimately disappointed by the lack of robust evidence that he perceived the specialty had produced in relation to symptom control.

> *Q: So tell me about the palliative care bit?*
> *A: I felt that when I came through my early years as a reg* [23]*, I saw lots of people dying with lung disease but an inability to get them into a hospice. So we couldn't get much palliative care for lung chronic disease patients so I felt that this was an underserved population. So for people with severe lung disease, transplant was thought of but not their symptoms or how they were going to die. Only a third would get a transplant. So I felt there was an unserved population and I wanted to be better at that. And I found out that the (palliative medicine) diploma was a really good way for clinicians to enhance their skills, so I did it alongside my registrar training.*
> *Q: Do you think you do do it better now?*
> *A: I think I went there looking for answers and the answers aren't there. I remember trying to find the evidence for management of breathlessness in the palliative care literature, thinking there should be trials of all the treatments, like with inhalers and there should be one that's best and you should have a sequential approach to it. But it wasn't there and it was the same across all the symptom groups. The palliative care literature just didn't have those answers for me. I was a bit disappointed that it didn't make me as much better. I think where it did improve me was my communication skills when talking with people at the end of life, because it did include videoing yourself during consultations. There was a lot of critique about what you said and how you behaved, it made me think a lot more about the words I choose, the questions I ask. But it probably didn't give me what I was looking for, I think. The communication side: I think I got the answers on enhancing myself and making me do it in a better and more sensitive way. Before, I'd never really reflected on what I was saying and I think I became much more reflective about my communication, but not my choice of the medicines I use. (Joshua, respiratory)*

Joshua likened the management of breathlessness to his own experience of the treatment of asthma with inhalers (for which there is a large evidence base). Apart from describing his disappointment at the lack of ‘good’ evidence in the palliative medicine literature, he highlighted another area that he felt he needed to improve in, namely communication. It is also relevant that he commented on his own lack of self-reflection before doing the course.

Not all the respiratory physicians found that communicating with patients was a natural or comfortable process. In the extract below, Erin described her initial anxieties about talking and listening to patients when she was a medical student, but that with practice and experience it became both useful and enjoyable.

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[23] Registrar: middle grade specialist training post

> *The clinical years were better, 'cos you get to talk to people, don't you? So they're scary and more difficult, but it was a new experience. I suppose when you're doing the clinical years, that's what you're wanting, that's what you're aiming for...*
> *Q: So it was a bit scary?*
> *A: Yeh*
> *Q: Was that the anticipation or the reality of it that was scary?*
> *A: So, I think it's the talking to people ... bit of it, that was quite a new experience. Just going to introduce yourself to people: "Can I come and chat to you for a bit?" that you do as a student. Prior to medical school, I was really quite shy and then I sort of came out of my shell in university and became a more confident person, but I wasn't prior to that. So that bit was a bit scary, a bit new.*
> *Q: Was that because they were older than you and sharing their intimate details with you?*
> *A: Yes partly, but also mainly having to go and chat to someone who has no need to chat to you, you weren't their doctor, you were going in and just putting yourself forward and going: "Hello can I come and chat to you about this?" But it passes doesn't it? But I enjoyed it*
> *Q: A pleasant surprise?*
> *A: Yeh, and then you get to chat to people and you become interested in their stories and their conversations and what they have to tell you and then try to work it all out and put it together. (Erin, respiratory)*

The last comment about people's interesting stories indicates that the medical interaction can mean more to the respiratory physicians than just fact finding. Erin described how she was entering into relationships with her patients as people with life stories, as well as bodies harbouring disease processes. The final quotation of this section also alludes to the holistic side of respiratory medicine, which the participant felt was lacking in other mainstream medical specialties, such as cardiology.

> *A: When you were doing GIM [24], they would say 'that's a good doctor, I would want to be treated by him or her.' Which felt like the respiratory doctors are always the good ones.They weren't just good physicians, they were good people, like they meant well. I always felt they were good people and physicians, genuine physicians not with tunnel vision which is what I perceive some specialties are like, such as cardiology. They focus on the ticker so that they forget the person. And I felt that respiratory doesn't do that. (Laura, respiratory)*

These observations from respiratory physicians would tend to indicate that while their natural inclination is towards a biomedical approach to the chest diseases that their patients

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[24] GIM: General internal medicine refers to managing unselected medical admissions, before they have been assessed and passed over to the appropriate specialty for ongoing care. Respiratory medicine is one of the specialties that participates in GIM on call.

suffer from, they believe that they are also able to accommodate a wider interpretation of illness and its impact on the whole person.

The palliative physicians' approach to the clinical encounter with their patients is different in many ways. In the previous quotation by Jennifer, as well as describing the joy of having the time to develop a close relationship with her patients, she also mentioned other important aspects of palliative care. She valued the multi-professional approach to patients, which is a central feature the holistic care (Doyle *et al.*, 1993; Cherny *et al.*, 2015). The next participant expressed similar values. She described how the experience of most of her GP attachments during training contributed to her holistic style, when she first took up a hospice appointment,

> … (I worked) … *in a hospice, but NHS paid. I loved it because it felt that everything that I'd done seemed to fall together, while I was doing that job. It drew on a lot of the experiences I'd picked up from my previous jobs, from my medical jobs, from my GP and caring for the family holistically, bit of psychiatry I suppose … maybe not the obs&gynae or paeds as such* (laughs) … *but again, dealing with the whole family and I felt I was using my MRCGP within palliative medicine. It, kind of seemed the last piece of the jigsaw, perhaps I wasn't subconsciously knowing how it was fitting together. It just seemed to fit, and I loved it.*
> *Q: And the features you loved …*
> *A: … were I think mainly the holistic side, the time for the patient, so the time to ask about them, the time to find about their families, the time to actually pull it together, to coordinate, to get it RIGHT for the patients and the families and to work alongside them for a period of time.*
> *Q: Something about the pace of the interaction?*
> *A: The pace and quality/intensity of the interaction as well.*
> *Q: So, it was looking at all aspects of the patients?*
> *A: And families. (Melissa, palliative)*

She used the words 'time', 'patient', 'family', 'care' and 'holistic' repetitively to emphasise what was important to her in her chosen role. With the patient in mind, I will next review the attitudes of the members of the two specialties towards patient involvement and choice in the healthcare relationship.

6.1.3 Patient-centred?

The notion of patient-centred medicine (PCM) was proposed in the late 1960s, initially within the GP community (Balint, 1969; Mead and Bower, 2000; Langberg *et al.*, 2019). It arose as an attempt to redress the balance in the doctor-patient relationship from the paternalistic biomedical model that was commonplace at the time to a more balanced relationship, incorporating the patient's own lived experience and preferences. In more recent years, the voices of patients have been further strengthened through the development of health social movements (HSM) (Brown and Zavestoski, 2004).

There is evidence in the transcripts of the respiratory doctors adopting a patient centred approach. In the first of these, the doctor expressed his gratitude to the patient for choosing to forego life-prolonging treatment in the face of distressing symptoms, to allow for a peaceful death with her family present. She was suffering from a progressive lung condition for which the only solution would have been a lung transplant, but no donor was available. He described how she clearly understood her illness and took ownership of her own death, choosing the moment when to have the oxygen removed so that she could die. This illustrates the 'partnership' relationship between patient and doctor as equals (Mead and Bower, 2000; Wirtz *et al.*, 2006; Scambler, 2018).

> *Another lady … whilst we hunted around for a potential transplant, she was also young, in her 40s, and the ITU staff were absolutely magnificent with her. Got to the point where they said to her "You can have the oxygen as much as you want, but if you take it off ..." and she asked: "will I die?"... "probably will"... "if I leave the oxygen on will I continue to live?"... "you might." And she pretty much asked for her oxygen to be removed in clear consciousness, she said "Can I have my family in?" And she spent a nice evening with her family, with the oxygen on, very very emotional. And then she chose to take the mask off and she died.*
> *Q: Did you get palliative care involved?*
> *A: Absolutely, they were absolutely magnificent. She had as much morphine as needed to make her comfortable. And she said "Once I'm comfortable, I'll take the mask off", and she did.*
> *Q: Was that a good death?*
> *A: That was ... wasn't for me* (laughs)*. I think it was as close under those circumstances a good death as one could possibly imagine.*
> *Q: How did you feel then?*
> *A: Helpless, as one often does, but very, very grateful for the help of good colleagues and very, very grateful for the patient. She could have made it very difficult for herself, she could have made it very difficult for me. I know it's not about us, but she was exceptionally clued up and understanding of what had to happen. Since transplant wasn't available, I wanted her to have a peaceful death. R1 male*

In the similar, but less extreme example below, Kimberley described an elderly patient with a presumptive lung cancer, shown up on a chest x-ray. She subsequently negotiated a plan with the patient and her family, explaining the risks and benefits of different approaches, but left the final decision to them. As in the previous example, she was happy and relieved that the decision of the patient and her family matched her own.

> *There's one patient in clinic who is extremely frail, just come back from a hip replacement after a fall, very, very malnourished, extremely thin, who was incidentally found to have a nodule on a chest x-ray and CT scan. It looked like malignancy. She's completely asymptomatic, it's a relatively small thing. And the debate with her and her family about what to do. Her and her family were initially keen to get this investigated and treated. Which I didn't feel was necessarily the right thing to do in terms of the potential benefit to her.*
> *Q: So how did you handle it?*
> *A: We talked through the nodule there, that it might be cancer, might not. We could do further investigations such as PET scans that might give more information. They all agreed that she wasn't fit for surgery if we were talking about curative treatment to remove it. There were alternative treatments with radiotherapy, but that had side effects with it and perhaps it would knock her back in terms of her symptoms and she was just recovering from another operation. They were very keen, but on discussion it became apparent what they really wanted was information about what it was.*
> *Q: Was this the family or her?*
> *A: It seemed to be mainly the family. It was partly her, but mainly the family who were doing the talking. Whenever I tried to get her engaged in the conversation, she seemed to be echoing what her family were saying. But I wasn't ever entirely sure I ever got to the bottom of what her underlying feelings were. The family were making a lot of the running of it.*
> *Q: How did you end up?*
> *A: We agreed that she would go for a PET scan to get more information and that she and her family would go away and think about what their priorities were and what they wanted to be done afterwards. The PET scan came back showing it was highly likely to be a cancer. As they came back they said "OK we've got that information now, having thought about the treatment and side effects of treatment and the fact that it's small, we actually don't want to do anything else." Which I felt a lot more comfortable with* … (laughs) … *I wasn't convinced that I would have been doing the right thing for her by operating. (Kimberley, respiratory)*

What is interesting in these two examples is the doctors’ evident relief that the patient, or family as her proxy, had made a decision in line with their own. This illustrates two of the dimensions of person-centredness, namely ‘shared power and responsibility’ and ‘doctor as person’ (Mead and Bower, 2000: 1187). It is evident that these two examples illustrate shared decision making in a constructive way. The question arises whether a similar approach would be appropriate in cases when assisted dying is requested. In the next example, Michael was describing how his experience of providing out of hours cover for a local hospice, whilst a GP trainee, was instrumental in his choice of palliative medicine as a long-term career. One feature that appealed to him was the patient’s choice not to accept the conventional medical treatment for a pleural effusion [25], which would be for him to go to hospital to have it drained. He described clearly how listening to the patient's wishes, even if they contradicted conventional medical opinion and practice was attractive to him, and he perceived that this was a feature of palliative medicine as opposed to mainstream medicine.

> *And then at the end of my last GP job, the bit I enjoyed most in GP in the whole time was palliative care and managing palliative care patients in GP. And I used to cover the* (local) *Hospice, and quite a few situations where you'd go in and see a patient there and you'd be astounded by the decisions some people were making ... Well: Pleural effusion ..."we can admit you to* (the local hospital) *to get it aspirated" ... "who says I want to go to hospital?" That was quite a defining moment in recognising actually, because someone was choosing not to go and have something drained. I had always grown up believing that people needed to have a needle stuck in them to have it drained off, and so then I rang round all the hospices in that part of England to see if they had any jobs going*
> *Q: So it was based on that defining moment?*
> *A: Yeh… that and a few others. Going to visit people at home and then ... the sort of conversations involved, rather than the medicine ... making decisions that would have been, you know, shocking in an acute sort of setting but deciding to, you know, somebody to stay at home … those bits, I think had made me think "there's something in this."*
> *Q: What were/are the aspects of palliative care that appeal to you most?*
> *A: I think it was the symptom control plus the conversations: the communications that went on. There was something around making decisions not to treat people* (chuckles) *... which was actually quite freeing in not following a particular pattern, so there was something around following what the people, the patients told you themselves, what they wanted as well as what the medical textbooks told you what you had to do. So it was a little bit of non-conformist bit of me coming out, sort of breaking the rules, doing things out of the box, doing things you know not meant to be done ... yeah ... you know problem solving stuff really, and the things we've probably lost quite a bit of since then …* (Laughs) *… (Michael, palliative)*

6.1.4 The medical encounter: summary

I have described and illustrated the medical worlds that the doctors specialising in respiratory and palliative medicine live in. They all share the intention to do the best that they can for their patients in the different environments that they find them. For the respiratory physicians, the environment is the cut and thrust world of acute hospital

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[25] A collection of fluid in the pleural cavity between the lung and chest wall. As the volume of fluid increases, it compresses the lung and causes breathlessness. Conventional treatment is to insert a needle into the cavity and draw off the fluid.

medicine and outpatients, where the aim of their care is primarily focussed on curing or ameliorating the diseases that their patients suffer from. Their care, therefore, has an orientation towards outcomes, and is based on evidence about treatments that have been subjected to scientific scrutiny. In contrast, the palliative physicians live in a world where people's lived experience of suffering is the principal currency. For them to understand this, the time to form close relationships between the doctor and patient is most important. They express an orientation towards people and their experiences. Whilst both specialties would aspire to patient centred care, the respiratory approach is viewed through a biomedical lens, whilst the palliative approach is primarily holistic, although both will adopt the alternative approach if they perceive it is appropriate. As both specialties are involved in the care of people with progressive illness from which they will die, it is now appropriate to move on to explore how members of these specialties view the issue of care at the end of life. This is with particular reference to the withdrawal of life sustaining treatments, how they might respond to requests for life to be shortened and assisted dying in general.

6.2 End of Life Care and assisted dying

One of the aims of this thesis is to explore and understand doctors' attitudes towards assisted dying. In this section, I am seeking to understand how the doctors that I interviewed reached their opinions. The first point to make is that 14 of the 16 palliative medicine specialists were clearly opposed to any potential change in the law to allow assisted dying (either assisted suicide or euthanasia) in the UK, and the other two indicated hesitant support. The respiratory physicians demonstrated a wider variety of responses, ranging from rejection, through uncertainty to theoretical support. However, even those who were most in favour of assisted dying held some reservations about it. Generally, assisted suicide appeared more acceptable to the respiratory physicians than euthanasia.

The process of forming opinions about assisted dying can be conceptualised by breaking it down into its component parts, and this is what I will now do. The elements of this process that I shall describe are personal values, the notion of doctors' duties, respect for the patient and her wishes and finally, respect for the law. In this process, I will seek to identify commonalities and areas of conflict that exist for the doctors when considering the issue of requests for assisted death.

6.2.1 Personal values

Generally, the doctors who rejected assisted dying expressed their opposition in terms of the value of human life, from several perspectives. These included Christian faith-based sanctity of life, secular values and communitarian and relational respect for the lives of fellow human beings (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018).

In this first quotation, Michael was explaining why he objected to assisted dying. He described how, even though he no longer practiced an active Catholic faith, the values of that faith still guided his moral responses.

> *Q: … What would be the main moral reasons for that, what guides you most?*
> *A: Probably my background. And I don't know that that guides me currently but that is why I've got to where I am and I'd struggle to argue myself out of it now. So I was brought up Catholic and the whole message of sanctity of life I think was very powerful.*
> *Q: Right so there's a religious ...*
> *A: That's where it came from but that's not necessarily what I you know ... I mean I don't sign up to all those bits now, yet I still have a hangover from that, which is difficult to shift. (Michael, palliative)*

Melissa also rejected assisted dying, but from a secular point of view, backed up by the current state of the law. She was reflecting on the difference between shortening life by withdrawing life sustaining treatment and euthanasia.

> *… I think it's so much more difficult to then go in to end someone's life prematurely when you're not withdrawing something.*
> *Q: Is that something about as a doctor ... your duty as a doctor?*
> *A: Mmmmm … I don't think it's as a duty of a doctor. I think it's as a person. You know legally murder and manslaughter is taking someone's life. So where do we have a boundary within that you know..People don't kill for whatever reason. You don't kill because their life isn't worth living, you don't kill because someone is awful to you, beat you up, murderer, rapist. When can we start saying "It's all right to kill". Because you start saying it's all right to kill and actually it's not all right to kill. (Melissa, palliative)*

The next participant, like Cicely Saunders, was a practising Christian. She viewed a person’s life as being special (compared to a dog) because that person was a fellow member of the human community, and of her own family. In these words, Michelle was expressing both communitarian and relational values in support of her rejection of assisted dying (Saunders, 2006).

> *You know when people and relatives say: "You wouldn't treat a dog like this"... But what I'm thinking inside is "We wouldn't treat a dog like this, but that's because you're a human and you're not a dog and I think the two are very different. And I value your life in a way that I don't … I think your life is much more valuable than the life of a dog … Or even if we don't get to the bottom of their pain or suffering or get them back home, they have time with family that they hadn't anticipated and actually that's incredibly precious … (Michelle, palliative)*

Later in the interview, she contemplated whether suffering might have some meaning, although she could not offer an explanation, other than it could not be a justification for shortening a patient's life.

> *Q: Do you think there are any people who's suffering is so persistent and unpleasant that shortening life would be beneficial?*
> *A: I think these are questions that don't necessarily have answers. I think how you answer that question will depend on not only what you think of suffering in this life and why suffering happens and whether it has any meaning to it or purpose. But also in order to decide whether ending life would be beneficial you have to have some thinking or thoughts about what happens when you end someone's life and what will that mean for them both physically and existentially. And the patients have to have some thoughts on that although some just don't want to think about it. The answer to "Is it better for me to end their life than them to remain in suffering?" I think often my answer would be: "Well I don't know that I have an answer to that question." I don't think I should be ending peoples' lives. In my mind that equates to killing somebody and it's not something I should be doing…*
> *Q: Does that come from a faith belief or an existential feeling about the value of life?*
> *A: I think there's both. I've had faith for a long ... several years of my life. (Michelle, palliative)*

This next quotation illustrates an alignment with a communitarian framing towards a fellow member of society (Selznick, 1987; Etzioni, 1998; Bell, 2016). Jason described how the specialty of palliative medicine allowed him to fulfil his role as a doctor. Although he was a practising Christian, for him the most important element of his job was the opportunity to form a relationship with a fellow person, rather than pushing his faith.

> *A: I think I've been really fortunate in having the kind of job that allows you to really value people who are struggling and in a very tangible way, to do something good for them. It's not about them looking for spiritual answers at all, it's just kind of having someone, who's hopefully a fellow human being, to spend time with them and have a bit of fun along the way, kind of stuff. Being able to be a human being, for me setting off, and seeing all the hospital specialties, I couldn't see how you could easily be a human being and a good doctor apart from in GP kind of stuff. But the joy of palliative care ... gosh, you can do a good medical job here and still be a good human being. (Jason, palliative)*

Whilst communitarian values respect the traditional structures of society (Selznick, 1987; Bell, 2016), relational theory focuses more specifically on the importance of individual relationships and the interdependence of people (Mackenzie and Stoljar, 2000; Kittay, 2001; Downie and Llewellyn, 2012; Norlock, 2019). The next quotation comes from a respiratory physician. Daniel was one of the two of that specialty who rejected assisted dying, but unlike the majority of his palliative colleagues, he was an atheist. For him, the importance of life was in the relationships that were developed and maintained.

> *Q: Some people would say that life has an intrinsic value of a secular nature, irrespective of any religious beliefs.*
> *A: I'm not religious at all. I don't believe in a God, I'm not sure what that really means, to say that life has an intrinsic value. I think I am a spiritual person in the sense that the things that really matter to human beings, the really important things are non-material. It's relationships with other people, it's love, it's things like that. That's really what life's about. But there's nothing magical about life per se. (Daniel, respiratory)*

Most palliative physicians opposed assisted dying, and their opinion was underpinned by views of the intrinsic value of human life. On the other hand, the respiratory physicians tended to express the view that people should have control over the circumstances of their life and death, and therefore were more likely to support assisted dying. The sentiments expressed below are an example of a liberal interpretation of individual autonomy, expressed in terms of the person’s rights over both her life and death. Interestingly, Ryan was the only participant who stated that he would be willing to perform euthanasia if it were legalised.

> *Q: And the reason you'd be supportive of it, assisted dying, I mean is...?*
> *A: I think you have a right to decide how you die. If you want to be supported and looked after and let nature take its course, that's absolutely fine there'll be systems in place to allow that to happen. But if you want to get to a point where you'll still be completely with it and able to say your final goodbyes to the family knowing that if you carried on, things were going to deteriorate. I think that's a personal choice people should have.*
> *Q: Some people believe that life has an intrinsic value. There are secular arguments and faith ones, in other words sanctity of life. Is either of those relevant to you or not?*
> *A: No, obviously I have a huge amount of respect for the value of life. But I also have a lot of respect for quality of death and I think that people should have the ability to talk about the quality of the death that they want to have if they know that death is inevitable. Death's inevitable to us all, but obviously for most people we don't know when it's going to be and it's some way in the distance. For those who know that death is likely to be in the next three or six months' time and that there's no likelihood of a different scenario, then I think they have a right to have a stronger opinion on the quality of their death. (Ryan, respiratory)*

It was evident from the transcripts, that palliative medicine's opposition to assisted dying was expressed in stronger terms than the respiratory physicians' support. Certainly, the assisted dying debate is aired widely in the palliative medicine community, so its members are better rehearsed and able to produce more sophisticated arguments than the respiratory physicians can, which will be the subject of the next chapter.

Another aspect raised by all the participants in this context, related to their own potential involvement in the act. The very term 'physician assisted' implies that they must be involved in the process, either by prescription or administration of the drugs used in the process. This was clearly of concern to the members of both specialties. In the next section, I will explore these concerns.

6.2.2 Doctors' duties

The notion that doctors should not kill is deeply embedded in Western medical practice. It was expressed in the Hippocratic Oath (Miola, 2007; Sokol, 2008), and some of the participants in this study alluded to this. Similarly, intentional killing is proscribed in UK law (Pattinson, 2011; Brazier and Cave, 2016; Herring, 2018). It is not surprising therefore, that even those respiratory physicians who expressed liberal autonomous opinions about euthanasia in general, were worried when considering their own role in the process. Over the following few quotations, I will explore these concerns in more detail.

At the one end of the spectrum was the only doctor, who when I asked him, felt that he could perform euthanasia.

> *A: Actually administering the treatment? …*
> *Q: Would you do it?*
> *A: I think if I'd been asked to be the independent person and there'd been the assessment and you were convinced personally that that's what they wanted. It was their wish and you were convinced by the suffering that they were in, then I think I could see myself being able to do it.*
> *Q: From a personal point of view, would writing a prescription feel any different to doing the injection?*
> *A: If your happy to write a prescription for a drug that will get given but as long as you're not actually the person giving then that's fine, but it's a bit naive to say there's a difference there. I think ideally you should be prepared to do both. If you're willing to write the prescription, you should be willing to administer it too. (Ryan, respiratory)*

What was interesting in his response was that having said ‘I think I could see myself being able to do it’, he expressed the rest of his reply as an abstract statement of logical deduction rather than an explicit personal opinion. The other respiratory physicians who were in support of PAD were more explicit in their concerns about being personally involved in the process. Laura described her ambivalence about helping her own mother, who wished to travel for assisted suicide.

> *A: ... I always thought it's their decision, if they want to end their life,* (or) *well have it ended. and I think we should support that. The difficulty I have then is the question "Would you prescribe the drugs yourself?" And that's when it really hits home because it's easy to say I support it and I always supported it and I've always found it very sad that in England it was a prosecuting factor limiting the families going with them* (to Switzerland [26])*. I found myself put in that position with my own Mum asked me about going to Switzerland with her. When it came to the question "Would I prescribe the drug?" I found myself thinking "Whoah" I think I would, but I'd have to ...*
> *Q: What about injecting the drug?*
> *A: That is even more difficult, I think. Because you're more physically involved in ... killing someone.*
> *Q: So maybe there is a difference?*
> *A: Yeh, I think so, Yeh. Because I think prescribing, yeh I think I would do that but actually giving it: I don't know* （whispers it）. *(Laura, respiratory)*

In her reflections on the ethical and legal issues involved, it was evident that Laura saw a moral difference between performing euthanasia and prescribing a drug for the person to take at their own volition. The idea of prescribing for her own mother was also shocking to her. What was clear was that there is a gap between abstract ideas of what is morally right and the reality of potential personal involvement. In the next quotation, Brian takes his thought processes a little further, when he considers it in relation to his own role as a doctor.

> *Q: Would you do it yourself?*
> *A: That bit I don't know. I do not know.*
> *Q: I feel an uncomfortableness there, what's that about?*
> *A: I think it's still in the background that although support it, part of my whole training up to now has been about trying to get people better, preserve life as much as possible. Although having said that life could be worse than death, actually being the one to physically end it does take a bit more thinking about.*
> *Q: Something about doctors duties are to treat rather than kill people?*
> *A: Yeh, some of that and I think in the background there's always the worry that if you are the one to take life being very clear it's the right thing to do. I think probably, if the*

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[26] Assisted suicide is not clearly regulated by law in Switzerland. There is therefore a small industry of ‘suicide tourism’ , mainly to the Canton of Zurich, in that country. Gauthier, S., Mausbach, J., Reisch, T. and Bartsch, C. (2015) 'Suicide tourism: a pilot study on the Swiss phenomenon', *Journal of medical ethics*, 41(8), pp. 611-617.

> *law was changed, it's something that I could see myself potentially doing. But I'm not certain. (Brian, respiratory)*

Brian had previously expressed his theoretical support for assisted dying, based on his personal liberal values of the importance of respecting a patient's autonomous wishes. Despite this, he saw his role as a doctor as being potentially incompatible with providing assistance in dying. To be actively involved would require him to be sure that it was morally correct. Similarly, Angela, who was one of the two palliative physicians tentatively supporting assisted dying, could not see herself performing the act although she felt that the option should be available. She quoted the influence of her faith and the Hippocratic Oath.

> *Q: You mentioned that you personally couldn't do it. What are the reasons you couldn't do it yourself?*
> *A: I just couldn't take life. It's everything combined. I think it's my culture, life is very very precious. I think it's my religion, albeit I'm not actively practicing it, and I think it's the Hippocratic Oath and what we're here for as doctors: forbidden to take life. So I think ... I went through this debate many years ago about abortion. There were abortion referenda in Ireland, I lost count of how many we had. I was in favour of abortion at that time, I wasn't even a qualified doctor … I couldn't do it myself, but I was in favour of people having the option to access an abortion if that's what would be right for them. (Angela, palliative)*

For all these doctors, it is evident that although they supported the view that assisted dying should be legally available for those whose suffering was unacceptable, there was a conflict with their perception of their own duties as a doctor. In contrast, moral reasoning for the doctors who rejected assisted dying on personal grounds was easier, because their personal and medical values were not in conflict with each other, as Amy explained. For her the conflict would begin with a change in the law.

> *A: I think, I personally do feel, and I suppose it's a moral thing rather than anything religious or anything like that. I suppose it just goes back to that sanctity of life.*
> *Q: So it's that life is precious and shouldn't be taken away?*
> *A: I think it's our role within that, as doctors, that's the bit I probably struggle with because it always comes back to the fact that the medical profession have to be involved. And I think that gives you a real conundrum, I suppose ...*
> *Q: Because doctors don't kill?*
> *A: Yes, and then if the legislation goes through, doctors would be asked to end lives under a certain set of circumstances. (Amy, palliative)*

Amy had formed her values independently of faith, and the following quotation expresses similar values to a Christian viewpoint. What is evident from both is that there is a congruence between their personal moral values and their perception of their duties as a good doctor.

> *A: So, it would stop me from feeling comfortable about prescribing or administering any euthanasia because for me, I think ending someone's life would both feel wrong but wouldn't be in keeping with what I value ...*
> *Q: Because doctors don't kill?*
> *A: Yes … but if other people chose to do that I would find it hard, but I would, I think be able to respect that.*
> *Q: So there's something about being a doctor that's ... or is it you as a person?*
> *A: Yes it's both. I think it's hard to separate them in some ways. I think I probably am,* (I) *have developed enough of myself as a doctor that I find it hard to separate them, em...but it's both what I value professionally and how I practice and the intent of how I practice which is to preserve life ... But from a faith perspective I wouldn't want to kill somebody. (Jennifer, palliative)*

I have indicated that for the great majority of the doctors interviewed in this study, the idea that doctors should not kill their patients is deeply ingrained in their perception of good medical care. In the context of requests for assisted dying, this sits in direct conflict with notions of respecting patient autonomy. For those who supported assisted dying, the conflict would exist within themselves. They would need to accommodate assisted dying within the kind of medicine in which they had matured as doctors. For those who rejected assisted dying, the conflict would be between the doctor who objected and the patient who wished her life to be ended. For the doctor in these circumstances their notions of patient centredness would be challenged by the patient's wish to take a path the doctor felt was morally wrong.

6.2.3 The patient's view

The evidence suggests that, for the most part, there are different views on autonomy between the respiratory and palliative physicians. The respiratory physicians tended to wish to respect their patients' autonomous wishes (Christman, 2004; Christman, 2018; Forrester, 2019), and the following quotation from Joshua illustrates the liberal approach to patients who might request assisted dying.

> *But morally, me, I think people should have the right to choose what they want, largely and so I believe that competent people should be able to choose what they do and if somebody has made a choice then we should be able to put in place ways of them achieving that choice. (Joshua, respiratory)*

However, like most of his colleagues, Joshua could not see himself performing the act, but he wanted to ensure that the option was available if requested.

> *A: I probably wouldn't see myself doing it, but I wouldn't be an objector to it. Somebody would have to do it. My role within this trust would be to make sure our patients could access it if they wished. (Joshua, respiratory)*

He described a situation, in which the liberal values of the society he lived and worked in were satisfied, without his own personal involvement in the parts of the process that he found distasteful (in other words, doing it).

Other respiratory physicians tried to put themselves in the place of the patients that might be requesting PAD when they were exploring the subject. The conflict with concepts of doctors' duties and good medicine were never far below the surface, as the next quotation illustrates, when Brian was reflecting on the doctor's role.

> *… I think, yes, as a general principle we should be aiming to preserve life and look after people, but I don't think that should be at the need of people suffering when they don't want to suffer. I can think of a variety of circumstances where if I were in that circumstance I would not want to be alive still ... (Brian, respiratory)*

Sometimes, the palliative physicians also agreed that for some individuals in particular circumstances, death might have been the best outcome. However, they did not agree that this would be enough to justify a change in the law. In this next extract, Matthew was reflecting on a patient that he had encountered during his higher training. The person concerned was experiencing extreme existential suffering as part of his cancer experience, which was unresponsive to drug or other therapies. In the end, the team resorted to deep continuous sedation until the end of the patient's life.

> *Q: So if we go back to the man you talked about as a trainee, who was distressed with his consciousness, if euthanasia was an option then, how would you have acted?*
> *A: I think if it was legal we would have had to offer it to him, and I think he would have chosen it. And that would have ended his suffering. For him that would have been a good outcome, but I'd have felt bad about it, the team would have done. I'm not sure about his family. (Matthew, palliative)*

Matthew offered a reluctant acceptance that euthanasia might have provided the best outcome for his patient, although he did not acknowledge that **he** would judge it to have been the best. Moreover, the palliative physicians who objected to assisted dying were unwilling to accept that the small number of apparently valid cases justified a change in the law, as Michael stated.

> *A: I think that the main thing for me is around that conflict between the respect for autonomy world, I sort of get it for people but there's something broader than that as well, there's something bigger than that that means that although that's what drives a*

> *lot of my care is people being able to say for themselves, there's also something that as a society we require to be able to trust our doctors to be able to know you are safe, and I think for me there are very few people, I won't say there are none, there are very few who are so fixed in their beliefs and their ways that they don't waver, most people I come across in the conversations I have change their minds quite frequently and I think that is the bit that makes me thing we shouldn't depend on people to tell us once and for all how things should be urm ... (Matthew, palliative)*

Whilst acknowledging that there are a ‘very few who are so fixed in their beliefs’ he still adopted Cicely Saunders’ views on the role of doctors in society (Saunders, 2006). What is clear in society and in medical practice is that doctors must obey the law (General Medical Council, 2013).

6.2.4 The law

For all the doctors who spoke of it, it was important to obey the law. This has been clearly stated in professional guidelines, whether about medical practice in general or about end-of-life issues in particular (General Medical Council, 2013; General Medical Council, 2019a; General Medical Council, 2019b).

In response to a question about how he would act in the event of a change in the law, Joshua indicated that he believed people should be given the choice to make informed decisions about their care, in other words, he described liberal autonomy (Christman, 2004; Woods, 2005). However, he was clear that his role was defined by the law, and that this would also define the limit of his actions.

> *Q: If it were to change, and it was legal, how would you respond to the patient who requests it?*
> *A: I think I would explain to them all their options in line with UK law. I'd put forward the options for control of their symptoms etc. and if they still wanted it I would say that that is within UK law, however that looked, I'd give the patient that choice too. Because deep down I believe people should be given ... I think my duty as a doctor is often to give patients all the information in a way that they can understand so that they can make their own decision. And I think that is often the challenge and so that's probably what I would try and do.*
> *Q: Some doctors would say that my duty as a doctor is to treat, not kill.*
> *A: I think my duties as a doctor are those as layed out by the laws of the land, so at the moment we don't kill. (Joshua, respiratory)*

It is interesting that Joshua viewed his duties as being dependent on the law, rather than any overall code of medical practice, such as the Hippocratic Oath. Melissa, the palliative medicine consultant quoted below, who had previously expressed strong opposition to any change in the law on assisted dying, also viewed the prohibition of euthanasia in legal terms as well as her own secular views on the value of life, to a lesser degree.

> *Q: Can I go back to these views; I think you said that "As a person I think that people don't kill." Is that right?*
> *A: Yes, I mean it's the law of the land. At the moment, people don't kill however bad* (the person is), *or whatever someone has done. People don't kill and however ill people are, we don't kill.*
> *Q: Some people are guided by things like spirituality/sanctity of life, faith, that sort of thing. Is that relevant to you or not, or is it a humanist type thing about people and killing?*
> *A: I think it's humanistic and legal: law of the land. (Melissa, palliative)*

When faced with exploring of how she might behave if the law were to be changed, Melissa altered her stance on assisted dying, suggesting that the state of the law would be influential on her attitude towards the intervention.

> *Q: If assisted dying were to be legalised in this country and someone were to say to you "I want to take it up." What would be your position on it, if it was legal?*
> *A: Well, it's interesting to look at the parallels with abortion, because when I was training in GP, there was one GP in the practice I was in who wouldn't refer for termination and would therefore tell them to go and see another GP, who would refer. And that to me felt WRONG because whatever your views are, if it's legal, as in termination within 24 weeks, that is something that is decided by the law. So I think we have to support that whatever my own views are. So if it were to be made legal, I would support the process that has been agreed and defined … I think we would have look what our roles are because actually, again in parallel with obstetricians, maybe that they feel uncomfortable doing it, but actually as doctors and that's part of our role how can every doctor then say "actually I won't do a termination" and it's left to one or two. But legally that is ... terminations are offered in this country (and) doctors are playing their role within those terminations. So if it was made legal and if experts felt that it was a service that was offered by the NHS then I think we'd have to look at what roles are expected to be played by what specialties. I think then we would have to be willing to play our part rather than say "not me". Because actually if it's offered legally then someone has to do it.*
> *Q: Would you be comfortable with it?*
> *A: It wouldn't be the bit I ... until I ... it would be difficult to know. My gut feeling is I wouldn't be comfortable with it, I wouldn't be comfortable about terminations. But actually you have to deal with them individual by individual at that time. It's hard to be ... generalise about something, it's so emotional. (Melissa, palliative)*

This response clearly illustrates the emotional and moral conflict that the doctor felt about assisted dying. On the one hand, she was uneasy about the concept of a doctor killing a patient, as she would have been about abortion, when she was in general practice. On the other hand, she acknowledged her potential duty as a doctor to be involved in the intervention, if it were to be legalised and if the law required doctors to perform it. What it seems to suggest is that she was considering prioritising the law and/or patient choices over her own underlying moral stance. In contrast, in the next quotation, Jason wanted to maintain his principles as a practising Catholic, by conscientious objection.

> *Q: If it were legalised, what would be your stance on it if somebody requested it of you?*
> *A: I think I'd have to make it fairly clear to them ... where I was coming from and my sort of stance. Which, I think, will seem possibly selfish to them in terms of: "Well you call yourself a doctor and you're not prepared to do doctoring things?" It might seem selfish from their point of view, but I just ... I think you learn to hang onto your soul, kind of stuff. (Jason, palliative)*

These last two quotations illustrate different approaches to handling conflicts between personal values and the law/patients' wishes. Melissa would acquiesce to her patient (if the law allowed it), whilst Jason wished to maintain his own values.

6.2.5 End of life care and assisted dying: summary

As with much of the data presented in these chapters, there were similarities and differences between the opinions expressed by the members of the two specialties on the topic of assisted dying. Amongst all the participants there appeared to be a deeply held unease about the active role of doctors in either euthanasia or assisted suicide. This was driven by the underlying belief that it is a doctor's duty to help people and preserve life, rather than end it intentionally. Similarly, both groups of doctors expressed a respect for the law and indicated that they must obey it.

However, on the issue of the morality of assisted dying for those who request it, there were clear differences between the specialties. The great majority of the palliative medicine physicians were strongly opposed to the intervention, and their opinion was underpinned by a belief in the intrinsic value of human life. For many this was a faith-based view of the sanctity of life, but others offered secular and communitarian values to support their attitude. In contrast, although most of the respiratory physicians offered tentative support for assisted dying if that was their patient's wish, there was much less certainty in their opinions. In justifying their own opinions, they were expressing the view that their duty was to respect their patient's autonomous wishes, whatever they were and even if that would not be their own personal choice.

The issue of assisted dying generates internal conflict for members of both specialties. For the respiratory physicians, their own medical values would tell them that doctors should not kill their patients, even if their suffering was intolerable. However, they would also ideally aim to respect their patients' autonomous wishes. Whilst the palliative care physicians would reject assisted dying, both from their own personal values and those of being a doctor, this would conflict with the patient centred approach they aspire to.

6.3 Conclusion

In this chapter, I have explored what care means to the members of the two specialties that I have been studying. I have examined two aspects of care that will inform the conclusions of the whole research project. In the first half of the chapter, the participants described what was important to them in their daily working lives and in their interactions with their patients. I have illustrated the similarities and differences in their clinical approach and described how the 'good' in respiratory practice was principally defined in terms of outcomes (getting people better), through a biomedical approach to illness. In contrast, palliative medicine aimed to improve the patient's experience in relation to her suffering, but in theory, not to influence her survival (World Health Organization, 1990). This, they would aim to achieve through a holistic approach.

When addressing the issue of assisted dying, the differences in attitude were more strongly apparent. The palliative physicians were mostly strongly opposed, and the respiratory physicians were undecided, but generally supportive of the notion. What was consistent amongst the whole group was a reluctance to be personally involved in the act of euthanasia and to a lesser extent amongst the respiratory physicians, assisted suicide. Both groups expressed the view that a doctor's duty should be to help their patient, but even those who supported the concept of assisted dying could not see themselves killing their own patients.

During the interviews, whilst discussing assisted dying and the doctor's potential role in the process, it became apparent that such dialogue was much more familiar to the palliative medicine specialists than their respiratory counterparts. The next chapter will explore this in more detail and explore why ethical discourse is part of the fabric of palliative medicine, but not considered to be so important by the respiratory physicians.

Chapter 7. An Interest in Ethics?

I have described the development of medical ethics in the UK, culminating in its incorporation into the medical curriculum in 1993 (General Medical Council, 1993; Doyal and Gillon, 1998). It is interesting that some of the (voluntary) ethical initiatives before that time, such as the London Medical Group (LMG), had been initiated within a Christian framework (Stirrat, 2015; Boyd, 2019). Indeed, Cicely Saunders herself was an early guest speaker at the LMG (Boyd, 2019). It is also evident from the publications of Cicely Saunders and other members of the palliative medicine community that ethics and ethical discourse are central to the specialty and its approach to medical care (Randall and Downie, 1999; Jeffrey, 2006; Randall and Downie, 2006; Saunders, 2006; Randall and Downie, 2009; Cherny *et al.*, 2015). The Association for Palliative Medicine (APM) is active in providing ethical advice, both on its website but also in the annual ethics study days that it organises (Association for Palliative Medicine, 2019a). Moreover, the APM offers position statements on a number of ethically contentious issues such as assisted dying and the doctrine of double effect (Association for Palliative Medicine, 2009; Association for Palliative Medicine, 2017). In this way, it seeks to form and maintain its doctors' attitudes to such issues. The Royal College of Physicians (RCP) did not develop a formal mechanism for providing ethical guidance until the formation of the Committee for Ethical Issues in Medicine (CEIM) until 1985 (Royal College of Physicians, 1985). The British Thoracic Society (BTS) has no committee or other mechanism for ethical guidance, although the respiratory medicine curriculum does require the trainee to 'demonstrate knowledge of the principles of medical ethics (Joint Royal Colleges of Physicians Training Board, 2020b). In this chapter, I will explore the doctors' attitudes towards ethical deliberation and discourse, and then illustrate how the doctors from each specialty approach ethically challenging clinical situations in their work. In the final part, I will discuss the concept of the doctrine of double effect (DDE) and what it means to these doctors, as it has potential relevance to care at the end of life.

7.1 Interest in Ethics

In this first section I will illustrate and discuss some of the participants' views on the value and importance of formal ethical study and deliberation, both before and after their specialist training.

7.1.1 Interest during training

A few the participants reflected on their experience of learning about ethical issues during training, before they had entered their final specialty. This might give some insight into any predisposition towards that subject, which would be independent of the influence of the chosen specialty.

In reflecting on her undergraduate course, Jessica made the point that of six students attending an extracurricular ethical discussion meeting, three of them, including herself eventually chose palliative medicine as their preferred specialty. She also implied that communication skills appealed to her, which had been identified by Angela as well, and was described in the previous chapter.

> *Q: What were the features of the course that you liked?*
> *A: This is an interesting thing because, communication skills wasn't really part of the course at that stage, ethics wasn't part either.* (Ethics tutor) *did a lunchtime ethical discussion group, it was a voluntary thing at lunch time. There must have been about half a dozen of us, and in that group there were two other people from my year,* (names them) *and we all ended up doing palliative medicine.*
> *Q: At that stage were you already thinking of doing palliative medicine?*
> *A: No, I think we were all interested in ethical things and it's interesting that we all ended up doing that. (Jessica, palliative)*

In contrast, the majority of those destined to become respiratory physicians did not share the same enthusiasm for the subject. There is a sense in the quotation below that although Kimberley had an awareness of assisted dying during her undergraduate course, it did not seem to be relevant enough for her to spend much time thinking about it as a student.

> *Q: During your training, either at medical school or later had you had much in the way of ethics teaching?*
> *A: Not that I recall, I remember the odd ethics lecture, but it wasn't a big part of things at all, no.*
> *Q: Did it cross your mind during those years, or were you just doing a job.*

> *A: Yes, in terms of ethics there was some discussion about assisted dying and things like that nationally. It wasn't something that I recall thinking about a lot. (Kimberley, respiratory)*

Joseph, reflecting on his time as a student, also offered a fairly dismissive attitude towards the formal ethical education that he had received as a medical student.

> *Q: During those undergraduate years did you have any ethics teaching at the medical school?*
> *A: We did. We had it as part of* (names a course module)*, which was a weekly session, and some of that included ethics, but it never went too deep, it was kind of superficial stuff.*
> *Q: Not greatly impressive?*
> *A: No. (Joseph, respiratory)*

One participant, who subsequently became a respiratory consultant, did get involved in an ethical debate as an undergraduate. In her defence of rational suicide from a viewpoint of autonomous choice (Woods, 2005; Maclean, 2013; Christman, 2018), Rebecca found herself at odds with all the other members of her peer group. Her point was that only the individual who was contemplating suicide herself, could understand her own inner feelings, and this would justify the act. This liberal view was typical of those expressed by her subsequent respiratory colleagues during this study.

> *A: I do remember when you mentioned this project, I remember doing lots of ethical stuff at medical school. And I remember having a debate about suicide, part of the course, and I think it might have been about assisted dying or something. And I remember being the only person arguing against a roomful of fifteen other people that suicide … it's very hard to judge as someone that is content, not necessarily happy, but content with your life … about the state of mind of someone that, what I think, is logically contemplating suicide. So how can you sit and say to someone "Your life's not that bad." If they feel that life is that bad, if they've lost their husband or wife. They're living it and some people, I think do choose suicide, they say "I don't want to live this life any more, it's too much." And it's hard for the other person to say "That's the wrong choice." The debate was "Is suicide the logical conclusion, an appropriate conclusion for some people." And my answer was "Yes, I think it is, in some cases."*
> *Q: So you were on one side and fifteen on the other?*
> *A: Yes. (Rebecca, respiratory)*

Within the limitations of a qualitative study, there is evidence to suggest that ethical deliberation was more valued by the palliative physicians during their undergraduate years. The one respiratory physician who did remember a significant ethical debate during her undergraduate years offered a liberal interpretation of autonomy, which in fact persisted, as was evident later in her interview.

7.1.2 Different interests

The difference in attitude towards ethical deliberation between the specialties is also illustrated in the next two quotations. In the first, the palliative medicine consultant was describing the events surrounding her own involvement in assisting the withdrawal of assisted ventilation from a man suffering from motor neurone disease (MND). The patient knew that this would result in his death, but he had found that his quality of life with the ventilatory support was unacceptable, and so he preferred to have it removed, and die.

> *So the next day it all felt a little bit more controlled. But in terms of ethics and the law, it was making sure that all the members of staff understood what was happening. And I felt very clear in that and make sure that the nursing staff didn't think that we were euthanasing somebody.*
> *Q: How did the nurses on the ward feel?*
> *A: Yeah, I think he'd been on there a while ... the nurse that was helping us, she got very, very tearful at the end, very tearful, but we spent some time making sure that she was comfortable with what we were doing and she seemed to understand. The junior doctors interestingly were not interested at all … (laughs) … never saw them at any point. I thought "This is an interesting thing, doesn't happen very often and there are some interesting debates to be had about the ethics and the legality of it", and it was just like "Yeh right." (Jessica, palliative)*

There are two points to make here. The first is how seriously Jessica took her own role, and how concerned she was that the nursing staff understood the morality and legality of the act and should have appropriate emotional support. The second is the surprise that she expressed when the junior doctors on the ward showed no interest at all in in the whole proceedings. Whilst she felt that the event justified a discussion of its morality and legality, the junior doctors had other priorities. The second quotation describes a very similar event through the respiratory physician’s eyes. In this example the patient had had an endotracheal tube [27] inserted to provide ventilatory support, but he wanted taken out, so that he could die in peace. Christina described her part in the management of the patient.

> *He didn't like it, he didn't want it … "Take this out." So we extubated him and he very quickly deteriorated in a whole sort of body fashion, so we re-intubated him ... we didn't know it was going to be so quick. I hadn't predicted that.*
> *Q: To ascertain from him him what he wanted?*
> *A: Yeh, so we re-intubated, checked what he wanted. He wanted it to stop.*

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[27] Tube inserted into the trachea and connected directly to a ventilator, enabling artificial ventilation

> *Q: Was he cross with you for putting it back in again?*
> *A: No he wasn't. As they often are at that stage, you want the family to be cared for as well. So then we re-extubated him with some anticipatory meds* [28] *and he passed away with his family. And they were happy with that. And a medical student who was there did an ethical poster and won a prize …* (laughs) *… about the ins and outs of intubating or not intubating in terminal stage disease, and then patient choice. (Christina, respiratory)*

Christina felt it important to make sure that the patient's decision was consistent over time (by re-intubating him and asking him again), and she was concerned about the welfare of the family, so she certainly displayed appropriate moral concerns over an irreversible and fatal act. However, she demonstrated a similar degree of surprise that an attending medical student should actually win a prize for a presentation on the ethical aspects of the event, as the palliative physician's surprise at junior doctors' disinterest in a very similar clinical situation. These quotations raise a question, which is whether the palliative physicians place 'too much' importance on ethical discourse, or the respiratory 'too little'. The observation could be explained by the participants' familiarity with the actual intervention. Certainly, Jessica had said earlier that it was her first time being involved with the withdrawal of assisted ventilation, whilst respiratory physicians are more familiar with its provision, so it is likely that they have also more experience of its withdrawal. Another point is that the idea of 'too much' or 'too little' places a normative standard on what may just be a difference in behaviour. In other words, the two specialties have different attitudes towards talking about ethical issues, but one approach is not 'better' than the other, as long as their actual behaviour in practice is equally ethically appropriate.

These extracts give some further insight into perceived differences between palliative and respiratory physicians regarding their moral framing of ethical issues in the clinical environment. However, both groups appeared to practice medicine with similar attention to providing appropriate care. The question remains, however, whether the palliative physicians' apparent immersion in ethical theory and discourse has a longer term impact on their clinical behaviour.

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[28] Sedative drugs to relax the patient before removing the ventilation

7.2 Ethics of Assisted Dying

The point of this section is primarily to demonstrate that the palliative care physicians had reflected carefully on the moral issues around assisted dying, and in doing so had constructed well thought out arguments, which they expressed during the interviews. In contrast, the respiratory physicians had not given assisted dying much thought, for reasons that will become apparent.

7.2.1 Assisted dying: a rehearsed argument?

If the palliative physicians valued ethical reflection more than those in respiratory medicine, it might be imagined that their arguments about morally contentious issues such as assisted dying would be better developed and more sophisticated. The next section explores this question.

All the participants were asked and expressed opinions on whether or not they supported a potential change in the law to allow assisted dying. In the following extract, Heather referred to the surveys of its members that the APM has conducted from time to time and confirmed that she voted in line with their recommendations (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019b). The Web material produced by the APM lists a number of reasons for rejecting assisted dying, one of which is the adverse effect that it would have on the perception of palliative care, and that it would be seen as a part of palliative care (Association for Palliative Medicine, 2019b). The statement below is an articulate interpretation of the Web material.

> *Q: Would you be in favour of there being a change in the law to allow assisted dying?*
> *A: I have voted in surveys by the APM on this, always against changing the law. The reason for that is because I feel it will harm more people than it will benefit. So many people are frightened of palliative care, the word Macmillan, hospice … that to introduce the concept that in any way palliative care might be related to assisted dying or euthanasia I think is to disenfranchise a large section of the population who are frightened of dying. For those whom it would benefit, I think they're in a minority, and for some of them I think they don't understand what palliative care has to offer. (Heather, palliative)*

Two of the sixteen palliative physicians were open minded towards assisted dying and this is the opinion of one of them. Angela had clearly thought very carefully about the issue, but unlike most of her peers, she supported a position of respect for patients' wishes. However, to justify her stance she proposed several caveats, including time to make certain that the request was persistent and the opportunity to have palliative care input.

> *Q: Do you think the law should be changed to allow assisted dying?*
> *A: I've really debated this in my head. REALLY debated it and I think, with the right safeguards in place, and that's the bit I don't trust the government to fund ... In an ideal world, with the right safeguards in place and a cooling off period and palliative care involvement so people could know what the alternative options are, if they're living with it and it should only people with advanced incurable disease. I don't think everybody should have access to it, just that subset of people. They should have to have a palliative care opinion to show what the alternative is. If what they can offer you will not meet your needs and a cooling off period then I do believe we should allow it. We would have to have the right safeguards. (Angela, palliative)*

The opinion just expressed was in the minority amongst the palliative medicine physicians, and the next two quotations are much more typical of my participants, who broadly reflected the stance of the APM. One of the palliative medicine physicians, Michelle, was so concerned about assisted dying that she wrote a letter to a UK journal expressing why she believed that it should never be legalised. She expressed a combination of arguments, all of which can be traced back to the ethical reasoning evident in UK palliative medicine literature and the APM Web material (Saunders, 1959; Saunders, 1992; Doyle *et al.*, 1993; Doyle *et al.*, 1998; Jeffrey, 2006; Association for Palliative Medicine, 2019b).

> *Q: What was the essence of what you wrote?*
> *A: The title was something like Physician Assisted Suicide goes against why most of us became doctors.* (It was) *about doctors don't kill, and also an experiential thing in terms of people changing their minds, the whole idea that to have PAS, people have to have a fixed and held belief. That is something that human beings don't have. We change our minds all the time, especially when people are feeling unwell, for all kind of reasons your perceptions and opinions can change. Also the concern about who's actually going to do this, for all kinds of practical reasons how will it be done. Doctors don't get trained in how to kill people. You can argue on practical reasons, I think. Practical reasons aside, from an existential kind of moral basis, I would deeply disagree with assisted suicide or euthanasia becoming legal. (Michelle, palliative)*

Underneath her empirical views about the inconsistency of peoples’ wishes to die, she referred to her deeper beliefs about the morality of assisted dying, particularly the doctor’s own role in the process. In the next extract, James was describing how he would respond to a request from a patient for her life to be shortened because of suffering. The values he expressed are very much in keeping with those of Cicely Saunders (Saunders, 2006). The other important point is that he acknowledged that he had not even considered the issue of assisted dying until he started working in palliative medicine, which was my own experience, and my stimulus for undertaking this research.

> *A: … But what we're seeing is a natural process of dying and there's nothing that we should do to alter that."*
> *Q: Because of the law?*
> *A: Because of the law, but also morally and ethically I feel that that would be not the right thing to do.*
> *Q: Morally and ethically?*
> *A: If you take a very black and white stance, killing is wrong. So it's wrong to seek to bring about somebody's death by whatever means to my mind and that's not something that I would ever want to associate myself with. So I see myself much more as affirming life and preventing suffering than seeking to actively end someones suffering by bringing about their death.*
> *Q: If they were to request it, does that make it any different to you?*
> *A: To me, I still see it as a black and white distinction.*
> *Q: What are the …*
> *A: So, although as I would describe myself as a religious person, I don't actively practice any religion. I think there's probably an internal moral and ethical compass that I have that would inherently say to me that that is not something that I should ever do or be involved in.*
> *Q: Have you always felt that, or not thought about it until you started doing palliative care?*
> *A: I suppose I've never really thought about it until I've been doing palliative care … (James, palliative)*

It is interesting that the last participant had not thought about assisted dying until he entered palliative medicine, but that during his training in the specialty he had assimilated most of the arguments that it offers (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019b). The next three quotations from respiratory physicians illustrate how little they have considered it at all. As an example, Robert had very little understanding of the definitions of some of the key terms.

> *Q: I'm interested in assisted dying* (defines the terms), *do you perceive there's a moral difference between them?*
> *A: (hesitates) … ermm ... Yes. I haven't thought about this enough. Physician assisted suicide implies that the patient has control of the situation. Euthanasia, I can imagine situations where there are patients who are unconscious but likely to live a while with a terminal condition. The patient doesn't have capacity.*
> *Q: That would be involuntary euthanasia. I was more meaning voluntary euthanasia*
> *A: Yeh, Yeh. In which case I don't think it's much different, no. (Robert, respiratory)*

Having expressed a liberal attitude towards the notion of assisted dying in general, Joseph was somewhat perturbed when asked to consider what his role might be in the process. It illustrates how, although he had had some sort of opinion on the issue, it was somewhat abstract and he had not thought through the implications, and particularly the emotional effect on himself.

> *Q: I do. Is there anything else you'd like to say about it all?*
> *A: Only that I've, kind of, surprised myself by ... without thinking about it too much if someone asked me: "Would you support assisted suicide?"... "Yeh, yeh, Dignitas: yeh, in the right situation." But then when you think about it: "Well, would I administer the drugs, how would that look?" It's a lot more complex. I still think I am pro- that side of things, but I'm a little bit surprised by how anxious I might be about it, having thought about it. (Joseph, respiratory)*

Crystal admitted that she had intended to read up and reflect on the issue of assisted dying before the interview but did not manage to do so. That she looked after dying people regularly, but had not considered assisted dying, suggests that either her patients did not request it very often, or that as it is illegal in the UK, she did not feel that she needed to think about the subject too deeply anyway.

> *Q: Thank you, is there anything else you'd like to say about it all?*
> *A: I think it's interesting, because I thought the interview was tomorrow, I was going to do a bit of reading to try and formalise my thoughts a little bit further. I see people that die all the time but it's not something that I've really rehearsed ... assisted dying. I don't really think about it hugely. It's interesting for you to ask me these questions because it highlights things that perhaps I do need to be thinking about a bit further and things are likely to change over the years ... (Crystal, respiratory)*

The point of this section is primarily to suggest that the palliative care physicians had reflected carefully on the moral issues around assisted dying, and in doing so had constructed fairly sophisticated views on the rights and wrongs of assisted dying. This, I propose, may be superimposed on an innate palliative interest in ethics, that I illustrated in section 7.1.1, and exists amongst the specialty as a whole. These anti-euthanasia views have also been strengthened by the British palliative medicine community through books (Doyle *et al.*, 1993; Doyle *et al.*, 1998; Randall and Downie, 1999; Jeffrey, 2006; Randall and Downie, 2006; Randall and Downie, 2009; Hanks, 2010), as well as journal articles (Saunders, 1959; Saunders, 1992; Saunders, 1995; Saunders, 2003). The APM has also been particularly active and influential in helping its members to form their ethical values through its ethics study days and web materials (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019b). In contrast, I have shown that the respiratory physicians had apparently given little thought to the issues around assisted dying during their training, or preceding consultant careers, until they were interviewed about it for this study. It is also evident that ethical theory forms a smaller part of the respiratory curriculum than in palliative medicine (Joint Royal Colleges of Physicians Training Board, 2019a; Joint Royal Colleges of Physicians Training Board, 2019b).

7.2.2 Assisted dying is too difficult to think about

Even though the arguments around assisted dying are almost routine within palliative medicine discourse, there were occasions when even these doctors preferred not to think about the reality of what would happen if it were legalised or what their role in the process might be.

Having reflected on his career in palliative medicine with satisfaction, particularly his caring role, Jason expressed his concerns about end-of-life communication and decision making if euthanasia were to be legalised and he was beholden to discuss it.

> *I do worry that this is an inevitable tide that will eventually be a legalised situation for euthanasia, and how much more complicated that'll make conversations around end of life and all that stuff, for people coming in. So I'm glad it hasn't come in so far in my working life. (Jason, palliative)*

Another palliative care physician, Jessica, had acknowledged that her opposition to assisted dying had softened as she grew older, from a clear certainty in her opinions to being able to see different sides of the argument. She described her ambivalence when asked how she would behave if the law were to change. Whilst she acknowledged the potential validity of some people’s requests, she also referred to her own uncertainty. It would be emotionally easier for her if assisted dying remained illegal.

> *So I think what I'm saying is I'm very conflicted. I don't quite know what I will do or what the right thing will be to do. Maybe that's one of the reasons I don't want it legalised is because I don't want to face all that dilemma. I have an instinct to do the right thing for the person in front of me and I get all the arguments, but I have a part of me that feels deeply uncomfortable, I suppose is what I'm saying. (Jessica, palliative)*

Although in general they were more accepting of the concept of assisted dying, some the respiratory physicians still expressed their concerns. In part, this was because in having the interview, they were forced to think about the issues and express their thoughts about their own role in the process, rather than just expressing broad liberal values out of context.

Kimberley described how the process of having to think in depth about the issues and explore her own values in relation to them was uncomfortable, but ‘good for the soul’.

> *Q: How did you feel about having the interview? Comfortable or uncomfortable*
> *A: Uncomfortable because of feelings of sort of coherence and trying to marshall thoughts. It is a difficult thing to think about. Am I uncomfortable thinking about it? “Yes,” but I had a feeling that it was going be good for me to think about things and express that. (Kimberley, respiratory)*

Another made no pretence of having thought about assisted dying. When asked about whether he perceived there was any moral difference between physician-assisted suicide and euthanasia, he replied:

> *A: Oh ... this is an area I haven't really ever sat and explored my views on because I've put it on the 'too difficult' pile and I've hid behind the shield of "we can't do it, so why bother?" I am not sure I can see a huge moral difference. It's a little like capital punishment isn't it? You've only got to get it wrong once. What ratio of innocent to guilty people would you be happy to accept for capital punishment? In the same way, if you got it wrong: the trajectory, the symptoms, the outcome may be different. I honestly don't know and I've probably deliberately not given it an awful lot of thought because I've just said "we can't do it, therefore I'll not dwell on it." (William, respiratory)*

As can be implied from the parallel he drew with capital punishment, William was one of the two respiratory physicians who clearly rejected assisted dying. His justification for not thinking about it was partly that, as it is currently illegal, he would not be involved in the process, but he also perceived that he had too much else to think about in medicine to be concerned with assisted dying as well.

> *I'm happy to say I've buried my head in the sand about this. To some extent it's because it's something I won't be doing, and actually on a day to day basis it isn't a clinical problem to me. Patients aren't coming, family aren't coming to me. On the basis that I can only do so much, can only think about so much, if I fill my brain full of that complex issue it'll push something more relevant out the other end.*
> *Q: It feels you wouldn't support a change in the law on assisted dying?*
> *A: I think that's probably fair. I think it's probably that I don't feel the need for it, based on my experience, not an understanding of the literature, or an in-depth understanding of other peoples' perceptions of it. I see probably more than my fair share of people who die of the diseases I've looked after and I just don't see the need …*
> *Q: So why do you think the general public are so supportive of it?*
> *A: 'Cos I think it's more abstract when they talk about it, I suspect. (William, respiratory)*

The other perceptive comment that he made was his interpretation of the degree of popular support for assisted dying in the UK, that it is easier to express an opinion on a controversial matter if it is theoretical rather than real. The same interpretation could be applied to respiratory medicine's higher degree of support for assisted dying as well.

Others, such as Christina, were not sure what their position actually was and preferred not to have to decide, as PAD is currently illegal. This type of attitude, of uncertainty and unwillingness to think about the issue, was expressed by several the respiratory physicians.

> *A: I don't know. I sway between both sides of the argument. It's almost easy while it's not possible and against the law. It becomes a very grey area doesn't it? Who would do it, how do you police it or regulate it. A bit like Brexit. If you say "Yes, let's do this," and then realise "Actually, how do we do it?" The standards and quality settings to make sure it's done right.*
> *Q: Do you think your attitude has changed over the years? Or had you never really thought about it before?*
> *A: I think we all mature and reflect more as we grow older ...*
> *Q: And have you changed?*
> *A: I think I've been always not quite sure, not definitely with it and not definitely against it. (Christina, respiratory)*

Some, however, expressed a more liberal attitude to assisted dying, but struggled with the practicalities of how it could be achieved safely.

> *Q: Thank you, is there anything else you'd like to say?*
> *A: I think it's a really interesting piece of work, but it's really hard. Because for me, I feel like it should be an option for people but actually the practicalities are so hard that it becomes ... it loses all ... it's like breaking a deadlock. It's more easy to say you're not going to do it because the practicalities of doing it are very very challenging and I don't like the idea that there needs to be a line and I don't know where it should be.*
> *Q: Isn't the nature of all laws that there are going to be challenges and changes, such as with suicide, male homosexuality, abortion?*
> *A: I agree, it should be an option for people, doesn't make any difference whether it's euthanasia or physician assisted suicide, to me they're the same thing. But it's just how to make that work the right way, which I think is the biggest leap. (Joshua, respiratory)*

I have provided examples from both specialties of the difficulties that the participants experienced when trying to conceptualise assisted dying. It appears that the palliative physicians had less difficulty with this than those from respiratory medicine. There are several possible interpretations of this. As I have already proposed, ethical deliberation and discourse are an important part of the palliative experience. Indeed, in the palliative medicine curriculum, within the section on ethics, is the requirement to be able to 'explain and evaluate society's dilemmas over euthanasia and assisted suicide' (Joint Royal Colleges of Physicians Training Board, 2020a). The ethics section of the respiratory curriculum is considerably shorter and there is no reference to assisted dying at all (Joint Royal Colleges of Physicians Training Board, 2020b). It is also easier to easier to express a view that is in line with the current state of the law than it is to attempt to define how a controversial change in the law could be safely regulated.

The ‘easy’ option as described by William was to ignore the debate altogether and as a doctor, to focus on the conventional aspects of his medical practice. In the data from this study, most of those respiratory physicians who supported a change in the law were viewing the issue from a somewhat abstract point of view, the expression of liberal autonomy for those who wish to have control over their own death, without proposing any mechanism for its delivery.

7.3 Ethical Frameworks and Assisted Dying

When they are making decisions in healthcare, doctors can draw on a number of ethical frameworks to guide them. I described them in the second chapter, so in this section, my aim is to illustrate some of them through the participants’ comments.

Whilst ‘principalism’ [29] (Beauchamp and Childress, 2019) is the most commonly taught framework in UK medical schools, other frameworks can also influence doctors’ actual decision-making. Of the four principles, respect for individual autonomy tends to dominate current day medical decision making (Brazier and Cave, 2016; Herring, 2018) and this is strongly influenced by liberal ideas of justice and equality in society in general (Kymlicka, 2002; Wolterstorff, 2012; Forrester, 2019). The other frameworks that are of particular relevance to healthcare morality are communitarianism and relational autonomy. Communitarian approaches to moral values have a long heritage in human history, are evident in the bible and in the reasoning of the Catholic church on moral matters (Bell, 2016). These values include respect for religious faith, the importance of family and other community social structures and of the importance of tradition. Autonomy has also been reinterpreted in terms of individuals’ interdependency, and this led to the idea of relational autonomy (Mackenzie and Stoljar, 2000; Christman, 2004; Downie and Llewellyn, 2012). In chapter 2, I gave a fuller exploration of these frameworks. In this section I aim to illustrate,

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[29] The four principles are autonomy, non-maleficence, beneficence and justice. Beauchamp, T.L. and Childress, J.F. (2019) *Principles of biomedical ethics*. 8th ed.. edn. New York: New York : Oxford University Press.

through their quotations, how the participants used these frameworks to form their own opinions.

Joshua used the ‘principles’ as a tool in his deliberations, the two guiding principles being autonomy and beneficence. After contemplating the nature of ‘good’ in the context of a request for assisted death, his conclusion seemed to be that for some life was worse than death, and therefore physician-assisted suicide could be seen as a beneficent act.

> *A: So, I have no religion and I think that there is in the Christian faith a strong feeling that it* (assisted dying) *is wrong and I don't carry that. I believe in beneficence, so probably for me, doing good and autonomy are really important … Maybe what you're talking about here is "Is physician assisted suicide doing good for that person because of their intractable suffering that can't be relieved, but also supporting their autonomy to choose." And you could argue that. For me that may be is this a competition between those two things and an idea of what is good. Is good giving people the choice to make their own decision to alleviate their suffering or problems in their own way? or is doing good keeping people alive as long as possible?*
> *Q: I think the question is "Could a living state be worse than being dead?"*
> *A: I think it's hard and about quality of life again. Can a tiny bit of quality of life be better than not living at all? There are clearly some people who are choosing in Europe or going to Dignitas that that isn't the right decision for them. They are making an active choice which presumably they understand that for them the life that they've got is worse than being dead. So some people are making that decision but it's hard for me to do that because it's like trying to imagine yourself ... but it must be for these other people. (Joshua, respiratory)*

The other point that he made, and which I will return to later, was that he acknowledged that he would accept a patient’s values (that some living states could be worse than being dead) even though he may not hold the same view himself. In response to a question about her potential support for a change in the law to allow assisted dying, Laura gave robust support for liberal autonomous choice. Whilst she respected sanctity of life for those who believed in it, she asked that people should respect alternative values if others expressed them.

> *Q: It feels like, from what you've said earlier, that you would support a change in the law to allow assisted dying?*
> *A: Yes. I think the main thing is that it's their responsibility and their choice, but also who are we to say "You have to live on like you are in distress and pain, whether it's mental pain or physical pain and suffering." Some of the patients are going through things I would never in my life let myself or my family members go through this. I feel very sad that this is criminalised.*
> *Q: Some people have views that life has got special value intrinsically. There are secular arguments about this and faith ones, in other words sanctity of life. Would either of those have any relevance to you?*

> *A: I'm not religious, I don't come from a religious background and I respect those people who have that view, but they need to realise that this is not a blanket thing. It's them and only them that it applies to. Fine, if they believe in the sanctity of life, fine but respect me for having my opinion and respect me for making my choices. Everybody has to make their choice in life. (Laura, respiratory)*

One of the strongest communitarian arguments from those who oppose assisted dying is the protection of the vulnerable in a society, who may feel themselves to be a burden to the others (Selznick, 1987; Bell, 2016). Their view is that society needs to look after these people, rather than provide mechanisms to get rid of them. Members of both specialties expressed this view, although more frequently by the palliative physicians. Sometimes it was spoken in very passionate terms, as in the next comment about assisted dying, from a respiratory physician, Daniel.

> *The argument against it is that I can't see how we could be absolutely confident we have adequate safeguards so people don't end up being coerced either by their own personalities or by their families or people who are dependent and would like them out of the way to get their inheritance. It is very difficult to see how we could guard against that. Because there are certainly some vulnerable people who would end up thinking "look I may as well just be out of the way here." They can be coerced or persuaded to feel like that. That would be utterly morally repugnant to me and I cannot see how you could guard against it … So I think we can't safeguard against those coercive forces to persuade the person to pursue that route and I would say that is too great a danger to accept all of the potential good in allowing an individual assistance with dying when they truly choose it. (Daniel, respiratory)*

Daniel expressed this view from a secular standpoint, but the majority of the palliative medicine participants held a Christian faith and therefore the importance of the sanctity of life and being able to live life to its natural end were very important as well. The next two quotations illustrate aspects of such values. In the first, Michelle described how she would respond to someone who wanted her life to be ended. She believed that even if the person did not value her own life, the caring person should still value that person and seek to protect and help them as a fellow member of humanity. This is in keeping with sentiments that had previously expressed by Cicely Saunders (Saunders, 1959; Saunders, 1995; Saunders, 2003; Saunders, 2006). However, it conflicts with the person-centred approach as it seeks to deny the dying person’s own priorities and preferences.

> *A: Well I would want to understand where they were coming from and what was leading them to such a sense of despair. Because I guess we face people in despair for all kinds of reasons all the time and we don't just say "Okay you're right, that sounds pretty bad, kill yourself." We try and do something about it, we try and help our fellow*

> *human beings. Whether it's getting their pain better, fixing a broken leg or whatever. We don't just say "Okay, you've decided, you're a rational being. If you don't think you are of any value, well you're not of any value to me." NO, we say "you're a human being, we should help you." … if they're presented to me as a patient I'm looking after, then I think the compassionate response is to try and understand where they're coming from. Not in order to coerce them into a different sense of understanding, but I think often we see in all kinds of ways of life that people can get into despair about different things and that doesn't necessarily stay the same, but can change and we need people to see that. (Michelle, palliative)*

The next quotation describes another view, also similar to that held by Saunders (Saunders, 1992; Saunders, 1995; Saunders, 2003), that people should be encouraged and supported to live their lives to their natural end, in this instance, Nicole was viewing the issue through her own Christian framework.

> *Q: You're aware that there have been attempts to change the law on assisted dying, what are your feelings about that?*
> *A: I don't think it should be changed, I firmly stand on that. The chap that comes into the press quite a lot is a chap on non-invasive ventilation for motor neurone disease [30].*
> *Q: What are the main reasons for you feeling that way?*
> *A: I just think we should be able to support people at the natural end of their life by whatever means, psychological support, physical symptom, socially, spiritual, whatever aspect of it is. Even without the palliative service, from the general practice perspective or hospitals there are people there to support people at the end of their life.*
> *Q: There's something special about life?*
> *A: Yes, it's not ours to take away. That probably comes from I was brought up in a Catholic background, I suppose.*
> *Q: So it's not ours to take away?*
> *A: No it's not ... my job is to preserve what there naturally is, rather than end it before it's naturally going to end. (Nicole, palliative)*

Her opinion was clearly driven by her Catholic faith, but she also described the elements of the holistic approach to care characteristic of palliative medicine. However, not all the participants who attached a special value to life did so purely from a faith point of view. The next quotation illustrates how, as Matthew matured, he realised the importance of his family and relationships over and above his existing faith in shaping his views on the value of life. His values, therefore, were shaped through both Christian and relational frameworks.

> *I think my experience of seeing people with terminal illness is that in time they re-invent themselves and their expectations change. I suppose I still feel that life is quite precious and having that ability to change your mind is important.*
> *Q: Is the preciousness of life a secular thing or faith based value?*
> *A: Both probably. I think having been brought up with a faith view, that shapes where*

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[30] Noel Conway: Unsuccessful legal challenge to allow assisted suicide in 2018

> *I'm coming from. But I think now, as a more mature adult, kind of having a slightly more eclectic view of faiths and having children and so on, I think I feel life precious because lots of people lose it quite easily. And therefore even from a totally non-religious point of view families and units and people being able to see through things, seeing grandchildren and so on is really important. (Matthew, palliative)*

Although medical ethics is largely taught at medical school with a ‘principles’ approach (Gillon, 1986; Doyal and Gillon, 1998; Pattinson, 2011; Stirrat, 2015; Laurie, 2016; Beauchamp and Childress, 2019), it is clear that the doctors drew on other influences as well. The data suggest that the respiratory physicians adopted respect for autonomy as their preferred viewpoint, sometimes using other principles to develop their arguments. In contrast, communitarian values such as the need to value vulnerable individuals in society, were the dominant motivators amongst the palliative medicine physicians. In the majority of these doctors, these values were underpinned by a Christian faith, either active or still influential. This lead to expressions of the sanctity of life and the importance of enabling patients to live until the natural end of their lives, a view also held by Cicely Saunders (Saunders, 2006).

In the next section, the focus moves from thinking and talking about ethical issues, and the frameworks that underlie them, to actual clinical practice. In this section I explore how the doctors managed ethically challenging situations through their descriptions of them.

7.4 Ethical Challenges in Practice

I have shown that the palliative medicine physicians valued contemplating and discussing the moral issues that underlie their clinical decision-making. The issue of assisted dying, although not a major issue for them, in terms of numbers of requests received per doctor, is also high on the agenda within this ethical discourse. Similarly, the rejection of assisted dying has become a dominant narrative in the output of the APM (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019b) and they have been active campaigners against any attempts to change the law when they have been proposed (Association for Palliative Medicine, 1993; House of Lords, 1994; House of Lords, 2005). Conversely, such thoughts and discussions are much less apparent within the respiratory community. A related area, arguably a more relevant one, is how the doctors in each specialty actually deal with ethically challenging situations in their own clinical practice. This section addresses this.

7.4.1 Withdrawal of life sustaining treatment

One clinical situation that was described by members of both specialties was when patients requested the withdrawal of life sustaining treatment so that they could die sooner, or because they found the treatment intolerable and acknowledged that its removal would lead to an earlier death. The specific example cited by members of both specialties was the removal of breathing support from people with end-stage motor neurone disease (MND) or chronic obstructive pulmonary disease (COPD).

In the first quotation, Michael described his own moral reasoning, and how he felt he needed to demonstrate this to the remainder of the multidisciplinary team to get their affirmation of the morality of the process of withdrawing ventilatory support from a patient suffering from MND, at his own request.

> *A: I felt clear that first: he was ok to be doing that. But secondly: we needed to be absolutely sure that that’s what he was wanting and that the rest of the team around were able to see or hear that that was what he was wanting. I ... I wouldn't say that I was comfortable, but I worked my way through it that that was the right or acceptable way of doing it.*
> *Q: Did you feel confident in your decision?*
> *A: YES I did. I still felt there was stuff that I needed to help with other people, to help them realise that we weren't breaking any laws here that we weren't ... err … and I think that in many ways ... they were almost conversations to … to the world around that we were taking this in a steady way rather than reacting to a man who said “give me a shotgun and finish me off”... it was almost about “you know I'm doing this calmly doing this in a way that we are as sure as we can be that this ... “*
> *Q: A team dynamic?*
> *A: yes, well I do quite a bit like that really.*
> *Q: So the other members of the team can be at the same speed as you?*
> *A: Yes, but also the fact that actually me doing that with other people makes me more likely to say that I'm bouncing this off other people, and depending on what reflects back, you sort of actually are “I'm right ... hang on a minute maybe I'm not right.” And we had a registrar here at the time who was very good at being able to almost, not agree with me, but actually bounce stuff back, that meant that I was checking my own thinking processes out against other peoples' which...which I think is vital. I don't think I can make these decisions in isolation. I think you have to be testing out, stretching the boundaries with the patient, with other members of the team. Actually he didn't have much family involved, interestingly I think his wife was around but almost just deferred everything to him so I think she would have gone with whatever ... (Michael, palliative)*

This quotation illustrates several points. Firstly, although he stated that he was confident in the decision, there is a thread of underlying uncertainty and concern running throughout the text. Secondly, in stressing how he involved the rest of the team in the process, although he implied that it was to help them in their understanding of it, he was also seeking affirmation that it was the right decision, for them to share the decision-making process with him. Thirdly, it appears that he would have involved the patient's wife if she had made herself available.

The next quotation also relates to the withdrawal of ventilation from a patient at his own request. Jessica's anxiety is evident in her words, although she said that she felt that it was morally appropriate. Her anxiety was partly because of the suddenness of the request and partly because she had not been involved in such a process before. However, with time and the help of guidelines, she accepted the challenge.

> *A: I suppose ... I don't think I felt uncomfortable ethically because I felt quite clear clinically, but it was a difficult situation. I recently did a controlled withdrawal of NIV [31], and I think the APM guidelines were very helpful. It all happened very quickly, so, I got a call from the home vent team [32] on a Monday morning to say "we've got a man on one of the wards." He had MND and was on intermittent NIV, in a nursing home but had some quality of life. Came in with a chest infection and just dropped off the cliff edge and really was significantly deteriorated despite treatment for the chest infection. He had a horrible weekend and was asking for the mask to be removed. He was saying "that's enough now", but he was totally dependent on it at that point. So home vent team said "can you come up and do a controlled withdrawal". And I've not done one before and I know other colleagues have done them recently but I hadn't. So there was that kind of panic: "I need to read all of this stuff, and I need to be confident and appear confident even though I've never done it before". We went up and I spoke to the man. It was one of those things where you had to be absolutely clear and blunt, just making sure that he understood the consequences and assessing his capacity and making sure that he realised that he would die with the mask off. We could communicate that and then he wrote on a piece of paper: "tomorrow." Which actually I was quite relieved about because it gave him a little thinking space and it gave me a little thinking space because it was all feeling a bit rushed really. That was the first time I'd met him, the home vent team knew him. (Jessica, palliative)*

The respiratory physicians did not appear to display the same degree of moral or practical uncertainty when supervising similar processes. In the next quotation, Erin described her

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[31] Non-invasive ventilation: A mask, placed over the nose and mouth, attached to a ventilator, to assist breathing.

[32] Home ventilation team: a community-based team of consultant anaesthetist and specialist nurses, who supervise patients requiring assisted ventilation in their own homes

attitude to removing assisted ventilation from patients with chronic lung diseases such as COPD. Her attitude was very much one of practical pragmatism and she did not appear to share the emotional turmoil that was expressed by the palliative doctors. A part of this contrast is likely to be familiarity with that clinical situation, as COPD is a common condition for respiratory physicians to manage.

> *Q: Can we move on to the ethical bits I'm interested in? I'm interested in ethically challenging clinical situations, like withdrawal of life sustaining treatments, such as NIV, can you think of one and tell me about it?*
> *A: I think the withdrawal of NIV I don't find that taxing because it's either working or it's not working. I've only ever met one patient that likes it symptomatically as a treatment, and I hate it whenever I try it. Generally people with COPD, they find it a very uncomfortable treatment. It's very restricting, they can't talk, they can't eat and it's not a nice sensation. So if it's not working then you would obviously stop it. And working is when it's making a difference that they're going to get off it and get home. I've never had a patient on it saying "I want to stay on it because it's making me feel better." I guess I've had patients whose families find the idea of taking the NIV off quite difficult, because they're going to die. But I think that usually when you have a conversation with them that this is not going to change that fact, this is just going to change the length of that fact then they're generally quite happy that you take it off and keep them comfortable in other ways. (Erin, respiratory)*

If the example just quoted seemed to be a routine event for an experienced consultant, the following one is not. Laura was describing how, when she was a trainee, she attended a patient in the casualty department whilst her consultant was busy in outpatients. She had to make a critical decision whether to perform an invasive, potentially life-saving intervention. The patient suffered from COPD, was being ventilated and had a pneumothorax [33].

> *Which now I had the dilemma of: I had a lady now on NIV, the family had at that point come in with lots of tears and hysteria. She was totally out of it, all the decisions we made were without the patient at that point in time. So I said to the family "There are two options, we can continue the NIV without putting a chest drain in but the chances of her surviving are very slim and she's in a very poor state." The dilemma I think that was ethical was "Do I put the chest drain into this lady in the last hour or two of her life and subject her and her family to that." I found that very, very hard and the consultant I rang, he was saying "You have to make that decision, I'll support you either way, but there is no right or wrong, you'll have to make that decision."*
> *Q: He didn't give you any steer?*
> *A: No and I'm glad he didn't, he said "I'll support you either way, there's no right or wrong, you can make that decision." He was totally stuck in clinic and couldn't come*

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[33] Collapsed lung, with air filling the pleural cavity. To resolve it, a tube needs to be inserted through the skin into the pleural cavity to drain out the air, this is usually a painful procedure.

> *out to make the decision for me. And I spoke to the family and I thought I would be guided by what they would want. And they begged me to put the drain in, so I said "Fine." And I put a drain in and she was discharged three weeks later.*
> *Q: And what did she say?*
> *A: She was glad with it, she was glad with it, and that always sticks with me because I was close to calling it, I was very close to calling it. And the family, they knew her better, and I said "It may prolong her life ..." but they begged me. And I don't regret it, because it turned out well. It could just as well have not worked ... (Laura, respiratory)*

The story had a happy end for all concerned. It illustrates a key part of respiratory medical training. This is to develop the ability to assess an acute medical problem, consider the therapeutic options, listen to opinions of the relevant interested parties and act in a decisive and timely manner. In such circumstances it is tempting to speculate that there would not have been the time to agonise for too long about the relative merits of different courses of action.

7.4.2 Conflicting opinions

The other area of ethical challenge in clinical practice was when there was a difference in opinion between the doctor and patient or family over the proposed course of action towards the end of life.

In the first example, although in theory, Jason could have chosen to withdraw the feeding tube, or not re-insert it after it had fallen out, he chose to defer to the patient and her family's wishes although this course of action was against his own judgement. His description of the attempts to put back the tube as 'assault' indicates how far he had acquiesced to their values over and above his own. As a Catholic himself, he would have been aware that he should not strive officiously to keep people alive (Clough, 1968).

> *A: I think the one where we, or I struggled most, was a lady who was the mother of a chap who was a doctor and* (also) *a Rabbi ... So she would hand over all the medical decisions to her son, and she needed naso-gastric feeding* [34]*, and this wouldn't stay down, and things weren't going very well. You were thinking "Gosh she's getting towards the end of her life. Is it time to be talking about … ? Shall we restrict the number of options we've got here, to just kind of …?"... "Just talk to my son" ... "No, no, no just carry on, we need to do everything we possibly can."*
> *Q: So they weren't really accepting what was happening?*
> *A: No, It was exhausting. I remember getting* (the senior consultant in the hospice)

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[34] Fine bore plastic feeding tube passed through the nose, down into the stomach

> *involved and just sort of saying "I'm finding this uncomfortable, will you come and see if we can make any headway with them." Which I didn't do very often, maybe not often enough, but ... she went home and then came back, and similar sort of problems continued for another couple of months on that occasion. We used to struggle enormously with having to … what felt like assault, basically, trying to put these tubes back down, treating the infections. Because that's what they wanted and she sort of said "This is what my son says is the best thing and he is a Rabbi and a doctor."… (Jason, palliative)*

At one level this quotation illustrates the relativism of ideas about the 'good death'. Whilst for the patient and her family, it was to live as long as possible, for Jason it was about not over-treating, but to allow her a peaceful death. At another level it illustrates how Jason had avoided conflict by acquiescing to the family, at the cost of a degree of internal anguish for himself.

Other clinicians were more confident in their position. In the following quotation, the comment about communication and disagreement would seem to imply that Christina felt she should just tell the family assertively what was going to happen, based on a clear clinical knowledge of likely options and outcomes, rather than the two-way communication style characteristic of palliative medicine.

> *Q: I suppose the other thing is things like, and I guess you see them in the ITU, turning off the ventilator for somebody or people wanting futile treatment and that. Disagreeing with patient or family on the way to go?*
> *A: So, I think if you communicate it well enough, you can not have the disagreement. I think that's why I like the lung cancer side and the pulmonary fibrosis side of respiratory medicine. It's either diagnosis, which is often awful, prognosis, which is often awful as it is with ITU [35] patients. If you communicate it well with a skill for that, you can avoid it. I don't think that I generate too many ethical conunundrums with relatives. Perhaps it's because I'm clear in my mind of what ... I know I'm a bit of a pessimist in terms of survival prediction for ITU patients but once they're in, you're treating them aren't you? (Christina, respiratory)*

Ryan proposed a similarly assertive approach in relation to patients wanting interventions such as cardiopulmonary resuscitation, that he judged to be futile. One issue seemed to be the knowledge gap between the doctor and patient, his experience of the likelihood of success against the patient's hopes and optimism. The other is the style that the doctor adopts in the interaction, paternalistic or negotiated.

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[35] Intensive therapy unit

> *A: I suppose there's lots of examples over the years, and there's a few themes that I think I've come across. There's one about some patients not being realistic about the extent of their disease and their prognosis. I particularly remember looking after some lung cancer patients where you start to have conversations about resuscitation etc. and their wishes. They very much want everything done and are a bit affronted by the fact that you're having that conversation at all. I would say they're the exception but those ones stick in your mind where you talk about that you've reached a certain level of futility with ongoing treatment and that the prognosis is poor and that if the condition deteriorated further, it would not be in their best interests to try and resuscitate them and move them to the intensive care unit. And trying to get that message across in a clear way of articulating, many patients will understand that. But you come across ones that just don't get it.*
> *Q: And how do you handle those ones?*
> *A: Sometimes I may say "We'll have to agree to differ in our opinions, but ultimately you can refuse a treatment we're offering you, but you can't insist on a treatment." That is quite a powerful way of getting it across in that if we don't feel starting cardiopulmonary resuscitation on them has any chance of success then it would be in our view the wrong thing to do and we wouldn't be prepared to do it.*
> *Q: Do you feel reasonably comfortable having those sorts of discussions?*
> *A: If the patient has a different point of view they can be uncomfortable, but you're confident in what you're saying and you have to be prepared to have difficult conversations. (Ryan, respiratory)*

The last two (assertive) examples, quoted by respiratory physicians, are examples of a paternalistic approach, based on the physicians' deeper knowledge of the intervention and that the law allowed them to refuse an intervention that they felt was futile (Jecker, 1995; Brazier and Cave, 2016; Laurie, 2016; Herring, 2018). In contrast, in the next example, the doctor concerned was a community-based palliative care consultant, one of whose roles was to discuss resuscitation status with home care patients. The difference in approach is very clear to see. Melissa's solution to the challenge was more of a person-centred approach rather than a paternalistic one.

> *DNACPR [36] can be ... you know, we're talking about resuscitation decisions, those can be tricky.*
> *Q: How do you initiate that type of discussion?*
> *A: I find it best if ... it's unusual to do it on the first interaction. That would be when you've built up a relationship with the patient. It's better if we talk about the more positive things we can do for the patient, reflecting how the patient feels at that time, what they understand about their condition, what are their wishes and their preferences for treatment. What are their wishes and preferences for help etc. How are they managing. It's about what's right for them, not necessarily living, and then we*

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[36] DNACPR: Do not attempt cardio-pulmonary resuscitation

> *would go on and say “what would support you doing this?” Then, “what you would not want for yourself?” So we start with what you WANT and then what you WOULDN'T want. So many times the conversation may be around people saying, recognising they're dying, recognising their wish to remain at home, recognising the need for symptom control, so part of that: how would we ensure that ermm … intrusive treatments would not start and often to support them. So that when we come onto the conversation about resuscitation many of them would say "yes please I'm very happy to do the form, please do that form to ensure that people don't commence it". (Melissa, palliative)*

In clinical practice, similar ‘ethically challenging situations’, such as withdrawal of assisted ventilation, seemed to provoke more anxiety and self-questioning amongst the palliative physicians, than it did amongst the respiratory doctors. It could be that the procedure was just more familiar to them: one palliative physician did state that it was her first experience of being involved in such a process. Another explanation could be that palliative medicine’s value of ethical deliberation encourages its members to be more self-reflective in clinical practice as well as in theory. The other difference between the two specialties seems to be in the style of communication, as is demonstrated in the quotations about withdrawal of life sustaining treatments, or ‘do not resuscitate’ decisions. The respiratory physicians preferred to use an assertive and direct approach towards their patients, as if giving the patient the facts of the matter and then allowing them to make their preferred choice. The basis of such an approach might be that the physician possesses the facts relating to the likely outcome and is therefore the ‘expert’ in an unequal relationship. The palliative physicians appeared to offer a more person-centred approach and involving the patient more obviously in the decision-making process. Having said that, both groups were seeking to facilitate the patient to make the decision that the physician wanted her to make.

7.5 Doctrine of Double Effect

The doctrine of double effect (DDE) is an important principle in medico-legal practice. It was first used in the UK in the defence of Dr Bodkin Adams, a GP who had been accused of murdering his patient (Devlin, 1985; Brazier and Cave, 2016). The theory of the doctrine concerns an act that may have two outcomes, one good and one bad and is described in more detail in the literature review. In the Bodkin Adams case, he was accused of killing his patient with an overdose of morphine. His defence was based on the proposal that his (good) intention was to ease her symptoms using morphine, a drug widely used for pain and breathlessness. The (bad) outcome was that she died from the depressant effects of the drug. The requirements for DDE to be acceptable include the stipulation that the intent should be to achieve the good effect, that the good effect should not be achieved through the bad one and that the need for the act should be proportionate to the likelihood of the bad effect occurring. In the context of end-of-life care, the DDE has relevance in the administration of opioids (drugs with morphine-like actions) and sedatives for symptom control, in the knowledge that they can shorten life. The other area of practice of relevance is in the withdrawal of life prolonging treatments, such as assisted ventilation for people who cannot breathe adequately, to sustain life. Palliative medicine commentators have been outspoken in their condemnation of DDE in relation to opioids (Sykes and Thorns, 2003; George and Regnard, 2007). For them, the key is in the intention, and they state that with appropriately safe dose escalation, palliation of symptoms with opioids can be achieved without dangerous respiratory depression. In other words, if a patient dies because of respiratory depression due to opioids, the doctor either killed her patient by intent, or was a bad prescriber (Regnard *et al.*, 2018).

In this quotation, Michael described an example of the doctrine of double effect very clearly. He had administered a sedative for extreme breathlessness and the young man died soon afterwards. Michael's anguish and self-questioning is very evident in his testimony. It is clear that his intent was to ease the patient's symptoms, not to shorten his life, but despite this good intention, he was still very uncomfortable about the outcome, many years after the incident.

> *.. and the situations where my actions have led to someone dying, not necessarily because (what) I've done at that moment in time, you know, when people die … erm … in front of you, you know, having given them some medication to relieve their distress. These are people treading a very fine ... I'm ... err ... slightly nervous about this being included ... (laughs) ... A Sunday afternoon: somebody dying in their garden shed as I'm administering midazolam*[37] *because of their respiratory extremis … um … you don't feel comfortable at the end of that, you don't think...you don't emotionally feel "this has been fantastic palliative care." I can rationalise that that was good palliative care, but ... but ... you still feel uncomfortable, you know. Whether this guy died ten minutes earlier because of what I gave him or whether he died a minute earlier because of what I gave him or whether he died ten weeks earlier because of what I gave him ... you still feel, you know, that's a massive thing to be doing but ....*
> *Q: But the man in the shed didn't necessarily want it?*

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[37] An injectable sedative of the class known as benzodiazepines

A: He didn't want it. He wanted to keep on living, but he wanted to be free of distress. He, he was going to die in the next hour from stridor
Q: but it still agonises you?
A: Yes, but it agonises me more ... erm. I mean he was in his 20s, it was his grandma's 80th birthday party, there were 30 people in the house, we carried him upstairs, he stopped breathing. I thought "shit, I should have brought some flumazenil [38]*." And then I thought "No, we had a conversation earlier in the week around the fact that if he developed an obstruction would he want a tracheostomy, would he want to go to hospital? No, he wouldn't, no he wouldn't." We'd cleared the way, but it still felt as if my administration of a drug had killed him. And I rationalised it by saying "I did not kill him; I simply took away the distress that was keeping him breathing." (laughs). (Michael, palliative)*

The other circumstance in which sedation may hasten death is when the person is too sleepy to eat or drink, and is not given assisted hydration, so is effectively dying of dehydration. It is generally recognised that it would take a week or two for this to happen (Printz, L.A., 1992; Miller, F.G and Meier, D.E., 1998). For this reason, doctors from palliative medicine conventionally provide clinically assisted hydration [39] to patients who are deeply sedated and who's anticipated lifespan is more than a week. In this quotation, Jennifer remembered an episode during her training when this did not happen. As well as expressing her unease at the fact that death might have been hastened by the lack of fluids, she reinforced the view that intent is all important in such circumstances. She also acknowledged that the patient really wanted euthanasia.

But as I'm talking, the person who comes back most is back in (hospice where she spent time in training). *I remember her saying "Just being awake, I don't want to be here ... every time I wake up ... I just don't want to be here. There was no pain, she was suffering from a fungating tumour, a gynae SCC* [40]*, and it was pretty horrific for her, but it was the experience of living she didn't want to endure. She didn't have any family coming in to visit her, I think she probably sent them away.*
Q: So she wanted euthanasia rather than sedation, did she?
A: Yes. And I think for that lady we used benzodiazepines [41] *to make her less aware ... umm … we didn't give her fluids because that wasn't what she wanted and she was dying of her cancer ...*
Q: So her life might have been shortened by her sedation?
A: Yes, it might have been ...
Q: Would the intention type thing bother you?
A: Yeh ... yeh ... I've thought a lot about sedation and intention and yeh, I would feel, I

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[38] Antidote to midazolam, which reverses its sedative effect
[39] Providing fluids, either by intravenous drip, subcutaneous infusion or feeding tube
[40] Squamous cell carcinoma: ulcerating cancer in the perineum
[41] Sedatives, such as midazolam

> *would feel concerned about that. So the intention for me in that situation would be to relieve distress and suffering and erm, doing that by reducing consciousness ...*
> *Q: So there was a bit of double effect almost?*
> *A: Yes, so I felt, would feel it myself. But in that situation I wasn't in charge. Erm … it felt uncomfortable, but ok. As a consultant, being in charge, I would feel very acutely uncomfortable about not giving fluids in that situation if I didn't think she was dying. (Jennifer, palliative)*

As I have indicated, the expressed intent of an act is very important to the palliative medicine doctors, and this also applies to the withdrawal of life sustaining treatment, such as assisted ventilation. In describing her involvement with one patient, Nicole, quoted below, was not willing to accept that the withdrawal actually shortened life but argued that he had died of the disease, that had been unnaturally prolonged by the ventilation.

> *Q: You might say that removing non-invasive ventilation in motor neurone disease is shortening their life?*
> *A: Yes, we've had this discussion recently. I feel like really, the chap I've got for example: the natural end to his life was probably 4 or 5 months ago now. So his life has been prolonged unnaturally by the NIV. He can't be off it for more than 2 or 3 minutes before ... Yes, I think that would be his natural end because he would die from respiratory failure, because he's got no movement from his diaphragm. Whereas if I was giving him a lethal injection when he was walking around it's still not the natural end to his life. (Nicole, palliative)*

Palliative care doctors tend to hold the view that they must not be seen to be intending to shorten life under any circumstances but should allow it to run its natural course. There were however instances where the participants did question even the morality of withdrawal of life sustaining treatment. In the following example, James eventually rationalised his concerns to a conclusion that was acceptable to his underlying values.

> *A: There's actually something that I'm dealing with at the moment. The gentleman has very advanced motor neurone disease, who is dependent on non-invasive ventilation at home … he felt that his quality of life had diminished to such a point where he didn't want to continue living. He spoke to me about the possibility of discontinuation of his NIV in an elective setting, as an inpatient ... when that NIV is removed* (we will ensure) *... that he remains settled, comfortable and symptom free, and be unaware of the process, which is his desire. But it is in someways difficult to ethically rationalise it. This is a gentleman who would, with continued NIV, continue living and he is asking for an intervention that means that he not continue living. If you think about it quite deeply, there are people that would say "Is this euthanasia, is this actively hastening someone's end?" Or is this actually a passive act in line with what the patient's wishes are, that means that they will die a natural death of the condition that led them to be ventilator dependent in the first place? And the more I thought about it the more I can think of it in terms of the latter … So there's something about setting the date for me that makes*

> *it seem almost more active than passive, because it's a planned event. So the planning behind that feels a bit uncomfortable. (James, palliative)*

The key to his being able to accept the morality of his intended actions was that withdrawal of an invasive intervention was passive rather than active. This was even though for it to be acceptable to the patient, he had to be sedated to unconsciousness before the ventilation was removed. This example illustrates the fine line that had been drawn by James to justify his proposed action. It would be the withdrawal of the artificial ventilation that would allow the patient to die (of natural causes), rather than the dose of sedation that would render him unconscious for that to be able to happen. In this next quotation, the same doctor described his response to a request from members of a dying patient's family for him to give extra morphine to 'ease the passing' (Devlin, 1985). His firm response was characteristic of the attitude that can be found in the writings of Cicely Saunders (Saunders, 2006). This would have been, in his mind's eye, to be actively hastening the end.

> *There has been a family of a patient who was semi-comatose at end of life and there has been a request from the family: "Can you give them a bit more morphine?" And another family member interjected "we know you would give them some more morphine to hasten things." These were perceptions I felt I had to challenge. I felt that's absolutely not what we do. So I said to them: "That's not something that we can do, we have to tread a very fine line between never seeking to actively hasten things, but also giving death a chance. Not trying to delay death or prolong suffering in any way. So what we need to do is focus on how your loved one is feeling and address things as they come up. Make sure they're free of pain, make sure that they're free of anxiety. But what we're seeing is a natural process of dying and there's nothing that we should do to alter that." (James, palliative)*

These five quotations from the palliative physicians demonstrate the attitudes prevalent amongst members of that specialty. These are that any active intention to shorten a life is wrong and that the aim of withdrawal of life sustaining treatment is to remove the distressing symptoms of that treatment rather than allow the person to die sooner. This is in keeping with Saunders' belief that people should be supported to live until the natural end of their lives, although withdrawal of life prolonging interventions is both moral and ethical.

In contrast, some of the respiratory physicians did show support of the notion of a generous dose of morphine or sedation at the end of life. It is relevant to note that these opinions were theoretical, rather than statements of historical fact of what they had actually done with one of their patients.

> *Q: Have you had patients with terrible symptoms who've asked you to help them on their way?*
> *A: I don't think I have, but I'm happy with the double effect of symptom control that may hasten events, more on the ITU. (Christina, respiratory)*

In the next quotation, Stephanie was discussing her own attitude towards doctors' potential roles in euthanasia if it were to be legalised. She had expressed her reluctance to see doctors performing euthanasia as it was not their duty, but accepted the idea of double effect, apparently as some sort of compromise.

> *Q: From your own personal morality, do you think it's something that doctors should be expected to do or do you think doctors' duties are different?*
> *A: Possibly the latter. Going back to my mother who was a nurse in the 50s, they were the days when Brompton cocktails were very commonplace. I would have no problem with that. To me that's different. There's a big difference between going a bit further with the kind of palliation or sedation concept ...*
> *Q: Sort of double effect.....*
> *A: Yeah, I don't have a problem with doing that. That's what I'd be most comfortable with ... (Stephanie, respiratory)*

These quotations illustrate that for the palliative physicians, it was important for them to state clearly that the intent of treatment was absolutely and only for the relief of suffering, and not intended to shorten life. On the other hand, the respiratory physicians were, at least in theory, more willing to blur the margins. The other point is that it is well established palliative medicine doctrine that with appropriate dose escalation, opioids will not kill patients, unless by intent (Sykes and Thorns, 2003; George and Regnard, 2007).

7.6 Summary

Society requires doctors to practice medicine ethically and within the law (Gillon, 1986; Miola, 2007; General Medical Council, 2013; Brazier and Cave, 2016; Herring, 2018). The data in this chapter suggests that overt ethical deliberation and discourse appealed to the palliative medicine physicians more than to the respiratory doctors, in other words they expressed an *orientation* towards this practice. Such an interest has been encouraged amongst the palliative medicine community and it forms a significant part of their literature and educational activity (Association for Palliative Medicine, 1993; Randall and Downie, 1999; Association for Palliative Medicine, 2019a; Joint Royal Colleges of Physicians Training Board, 2020a). This does not necessarily signify that the respiratory doctors act less ethically in practice. It is likely that there are other influences on how they develop ‘good practice’ than the ethical frameworks that I outlined in chapter 2. I will explore these influences in the next chapter.

The palliative medicine physicians have expressed concerns about assisted dying and its morality, and these attitudes can be found in the writings of Cicely Saunders (Saunders, 2006). They are now championed by the APM, which also provides structured guidance on the reasons for its opposition to it (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019b). In contrast, the respiratory community were largely unrehearsed in ethical arguments, and did not see assisted dying as a particularly relevant issue in their clinical practice. This was in part because requests for assisted dying are uncommon and in part, because it is illegal anyway. They approached the ethical issues that they encountered in clinical practice with practical pragmatism and were not as concerned with contemplating the underlying moral theory as their palliative counterparts. On the *spectrum* of ethical discourse, their *orientation* was towards acting rather than talking.

The data suggest that the palliative physicians viewed the doctrine of double effect very seriously, from two perspectives. These are firstly, the absolute importance of expressing an intent of palliation (as opposed to shortening life) when describing an intervention which might accelerate death, and secondly that the generous increasing of morphine dose towards the end of life is unacceptable (James). These dictums are part of the fabric of palliative medicine. In contrast, those respiratory physicians who offered an opinion on the subject, appeared more relaxed about the idea of ‘easing the passing’ (Devlin, 1985).

Chapter 8. Influences

In this chapter, I seek to explore the influences that may have shaped how the participants responded to the issues that were raised during the interviews. I will approach the question from two perspectives. Firstly, I will explore the participants' own perceptions of their motives for entering medicine in the first place, which might give insight into their underlying personalities. Secondly, by considering their reflections on their training, their interactions with senior members of their specialty and with their specialist society (if relevant), I will examine whether and how these relationships influence the participants' attitudes and values in relation to my areas of interest.

8.1 Characteristics of the Person

The themes that I am presenting in this chapter are based on my interpretation of the participants' recollections of how and why they chose to study medicine and become doctors. In their interviews they also reflected on their medical student and 'junior doctor' years, before specialisation. This will provide some insight into the personalities and values that these doctors possessed before entering their chosen specialty. What I am exploring is whether the participants had characteristics which predisposed them to choose the specialty that they eventually did. I have already indicated in the literature review that while members of each specialty do share many values, they also express some differences, so I am trying to see whether their individual values complement those of the specialties that they subsequently joined.

Studies over the last 30 years, exploring the reasons for students' choices for studying medicine have illustrated several potential motives. These include an interest in science, having had academic success at school, and the perception that medicine is a secure and prestigious profession, which offers a good salary. The other important motivator that the studies have identified is an altruistic one, often expressed as an interest in helping people (Hyppölä *et al.*, 1998; Vaglum *et al.*, 1999; Heikkilä *et al.*, 2015; Wouters *et al.*, 2017), in other words, an orientation towards people. Vaglum (1999) reported that women were more likely to be people oriented, but there have been no studies comparing different specialties within medicine.

I have identified three themes from my analysis of this data, which I have named ‘A vocation’, ‘A leap of faith’ and ‘Perks of the job’. Participants often described more than one motivational factor, so they are not mutually exclusive.

8.1.1 A vocation

For the purposes of this thesis, my understanding of vocation is as defined in the Oxford English Dictionary, namely: ‘ A profession, way of life, course of action, etc., which a person feels that it is his or her duty or destiny to follow, or for which he or she feels particularly suited’ (Proffitt, 2018). The point of this definition is that it includes a moral component to help or serve as well as an aptitude for the work. I do not refer to the notion of a vocational degree, in which a particular career follows naturally from the chosen degree, such as dentistry. Amongst the participants, all the palliative physicians, and ten out of the sixteen respiratory physicians described some sort of vocational motivation in their decision to study medicine. and, as I will show, there was some overlap between them.

8.1.1.1 Care

Many of the palliative medicine physicians used the word ‘care’ in their recollections of how they had come to study medicine. In contrast, none of the respiratory doctors used the word or described an experience of giving personal care. In this first quotation, Nicole described the influential factors underlying her choice of career, but her principal motive was her mother and a perceived need to care for people.

> *A: My mam was probably the biggest influence, she was a nurse. She'd also worked for social services with children at risk. So I'd always been brought up in a very caring environment. I'd also had personal experience, my brother was very ill throughout childhood a couple of times after an accident, then after meningitis he had neurosurgery. So we had a lot of contact with medical professionals. It came from there. I found as I went on I was definitely interested in people, quite caring towards people. So those things just fell together ...*

The childhood experiences of her brother’s illnesses and having a nurse as a mother were clearly important in her decision making to pursue a caring career. She had already indicated an interest in science as well, and this combination led to her choice of medicine and subsequently palliative medicine. In fact, four of the palliative care physicians had mentioned that their mothers were influential in their choice of a caring career. Michael acknowledged this fact in describing how he changed course to study medicine, because it involved caring.

> *A: … I decided that's what I wanted to do and I went along to the admissions tutor here, and he said as long as I filled in an UCCA*[42] *form you can start next year, as I'd already got the grades. And what made me do it was more the scientific stuff plus the caring stuff. I mean I had done a lot of voluntary work as a student with children with learning disabilities and spent nine months as a care assistant, so I'd got quite a lot of care background. My mother had been a PE teacher and had talked most nights about anatomical and physiological things that she had studied and clearly was directing us … (laughs) ... from an early age. So I think that that combination of the scientific stuff and the care stuff was what made me want to do medicine really. (Michael, palliative)*

For both participants the important motivators were an interest in science and a wish to care, and both mentioned the influence of their mothers. In the next example, Jessica described a 'light bulb' moment when she realised where her vocation lay, and she changed courses to fulfil it.

> *A: A bit of a random story, my father was a GP and he didn't really enjoy his latter years. I saw that and decided to do sciences at university and then I had a year off and in that year I went to India and worked in one of Mother Teresa's care homes and absolutely loved it. Also in that year I had a job as a domestic in a hospital. It was a kind of moment: one evening, I was cleaning in theatres and I could see this operation going on and I just thought "That looks incredibly exciting". Everything just fell into place. So at that moment I decided I'd try to switch courses.*
> *Q: Can you tell me about your experience in India?*
> *A: I was ...* (hesitates), *quite an ernest person …* (laughs)*, and I wanted to do good work and care for people, make a difference and so I volunteered to do this. It was six months organised, we were paired off and put into schools in fact. Initially it was teaching, but then I met local people and I still really, really wanted to ... I met Mother Teresa as well. That was an amazing experience. We visited one of her homes. I was with a group of people and that group, I remember, walked in and there was lots of people on mattresses on the floor. Because it was like a warehouse with mattresses on the floor. And everybody was a bit shellshocked, stood there and didn't know what to do. So I thought "well, I can't speak the language, but I don't want to stand and stare at them", so I just sat down on a mat with a lady and we had an exchange about hair and she started doing my hair. It was just a really powerful moment. I realised that, having been fairly under confident, that I could do things, I could be brave enough to do things. It was a caring sort of a role. Then I went back, helping give out meals, helping with*

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[42] Universities Central Council on Admissions, now known as UCAS.

> *children, doing basic care, changing nappies and that sort of thing. So it was all pretty basic and all pretty unsupervised 'cos it was a huge home and not many helpers, so I just mucked in. (Jessica, palliative)*

It is interesting that Jessica had initially rejected medicine because of her father's dissatisfaction with general practice, but that she had then found her own motives to pursue the same career. These were clearly of a vocational and caring origin, although also stimulated by the drama of the operating theatre. The sense of destiny (that she had found her vocation) in this extract is reminiscent of Cicely Saunders' own decision to study medicine, based on her relationship with David Tasma, his subsequent death and her mission to improve care for the dying (du Boulay and Rankin, 2007). The features of the care that she described so clearly were its personal nature and its reciprocity, as she sat down with an Indian woman with whom she could not communicate verbally, and they groomed each-other's hair. Such a relationship between carer and cared-for is characteristic of the ethic of care (Gilligan, 1993; Noddings, 2003; Norlock, 2019). In describing herself as an 'earnest person', she also alluded to her own values, which in addition to doing good work, included a strong Christian faith, which also resonates with Cicely Saunders (du Boulay and Rankin, 2007). She finished her interview with the following observation.

> *A: It's been interesting. Interesting to see where your values come from, from being a young person. My faith was very much from an experience I had in the sixth form, there was a really good group of people and it became like really … really ... I was a bit over the top actually. It's still there, just more mellow …* (laughs). *(Jessica, palliative)*

All these participants described caring for people at an individual level, and in the third example, at a physical level. She also described going to do voluntary work in the Global South, an activity shared with other participants who subsequently entered palliative medicine.

8.1.1.2 Visiting the global south

Four of the palliative medicine physicians described undertaking voluntary work in India, and one in Tanzania at some stage in their earlier lives, but only one respiratory physician went to India. In the next extract, Heather described her experience during an undergraduate student elective period. Her experience mirrored the personal physical care described by Jessica. It was clearly a profound experience for her.

> *And part of my student elective I went to India, and in Calcutta I worked with Mother Teresa and nurses in their care of the dying home. I was moved there. Very little*

> *medicine went on, but there was a lot of care, and in their homes people were brought in off the street so they could die on a hard metal bed. They would have a cup of cold water offered to their lips or someone just holding their hand or mopping a brow. I found that extremely moving and powerful. My duties were mainly as a carer. Sometimes people would come up to you ... there were only a couple of trained doctors, so the nuns might ask you a question "Do you think we should give something for this?" And you would say "well yes" or "no, I don't know", but by and large it was simply just care. (Heather, palliative)*

Christopher also went to India, during his student elective period. His description appears to indicate some internal cynicism about his motives, and the experience did not seem to have made such a lasting impression as the two described earlier. However, his final comment seemed sincere and he did end up specialising in palliative medicine.

> *Q: As an undergraduate did you have any idea what you wanted to do in the end?*
> *A: I kept my options open. Interestingly I did do a month in a hospice* (names it)*, one of the things I chose to do for my elective was to work at* (hospice) *for a month.*
> *Q: What drove you to do that?*
> *A: As I told you, my brain was poorly formed, but I think I must have had some notion that palliative medicine might be something I would do. But I went to India for the other three months and worked in a mission hospital. So I think I had grand plans of wandering the third world saving the sick. So principally keeping my options open.*
> *Q: And a bit of doing good in there ...*
> *A: Absolutely, lots of doing good in there. I think making a difference and doing good is very important. P14 male*

However, Christopher did not describe the close personal care that the other two who visited India had done, but he did refer to the more abstract concept of ‘doing good’. I shall consider this and the other related notion of ‘helping people’ in the next section.

8.1.1.3 Doing good and helping people

Both palliative and respiratory physicians referred to these types of motivation although it was more evident in the palliative transcripts. In the first quotation, Angela described her idealistic interest in helping people that dated back to adolescence, and linked it with her self-perceived communication skills. The individual care that appealed to her was of an emotional nature rather than physical. This is one component of the holistic care approach that exists in palliative medicine (Cherny *et al.*, 2015).

> *Q: Did you have any thoughts about what being a doctor might be like?*
> *A: Yeh, but they probably weren't very accurate. I was really interested in health and reading up about it. I suppose I had that altruistic thing that a lot of teenagers have that you want to help people. I definitely had that. And I definitely was a go-to person for anybody who has a problem.*

> *Q: They liked talking to you*
> *A: Yeh, so I knew I was able to communicate well even though communication wasn't highly regarded. (Angela, palliative)*

Communication and an interest in the holistic aspects of healthcare are also evident in the next statement about a student attachment in general practice as described by Jennifer. She was describing her preference for a bio-psychosocial approach to illness during her undergraduate career, and she also later specialised in palliative medicine.

> *Q: What were the things that appealed to you?*
> *A: So in the clinical, there still wasn't much* (patient) *contact, but I can remember particularly enjoying the GP attachment and going to see people in their homes. I think we went in pairs to see people at home and we wrote it up as a project as a special study module, and I liked hearing people's stories and understanding that illness in the context of the person and what it meant to them and what it meant they couldn't do and what they did. It's quite a vivid memory of enjoying that time.*
> *Q: So it's listening to them and their story and how it impacted on their lives?*
> *A: Yeah, yeah ... absolutely. (Jennifer, palliative)*

James described two characteristics that I will explore further later, intelligence and a love of science, but the overall impression in his interpretation of why he chose medicine was of someone who wanted to help people to feel better, which is very much the focus of palliative medicine.

> *A: After my GCSEs, I got good results and I thought "The doors are open here, what would I really want to do?" And I thought: "medicine". My mum was a nurse, so she had some experience in working in healthcare, so I organised some work experience. And thought "Actually, this is something I could see myself doing." I loved biology, I loved working with people and it Just seemed to be the right path.*
> *Q: What did you imagine medicine would be like?*
> *A: What did I imagine? I think I would see myself as a scientist in some ways, so I do have a science based focus on things. I like knowing about biology, how people work. So it was actually the ability to apply that in a job role that I could actually do something and make a difference, make people feel better ... all of those kind of things.*
> *Q: Something about doing good?*
> *A: Yes, definitely. So definitely wanting to do good within a job role. (James, palliative)*

The other interesting observation about what James said is that, like two of the participants quoted previously, he was positively influenced by his mother, who had been a nurse. The next extract, from a respiratory physician, also aludes to nursing, but from a different perspective. Laura felt that her academic ability would be of more use in medicine than nursing.

> *Q: And what is it about medicine?*
> *A: I wanted to help people, I felt I had more to give than if I had been a nurse, because I had thought about it, but nursing wasn't for me. I'd done various internships during my high school years and I thought I wanted to do more, I wanted to do the cleverer side of things.*
> *Q: So there was something altruistic, about doing good? and using your mind?*
> *A: Yeass ... but not science particularly. (Laura, respiratory)*

The notion of helping people, as expressed by this participant is difficult to characterise, other than it would involve the use of her intellectual ability, which she perceived would not be adequately utilised in nursing. In describing his desire to make a 'valid contribution to society' Daniel, a respiratory physician, described a more abstract motive for his choice of career. He was the only participant from that specialty to have done voluntary work in the Global South, although he did not describe what he did there. He was also the only person from either specialty to acknowledge his need for a good income.

> *Q: Can I start by asking how you came to study medicine?*
> *A: When I was 18, I'd never even thought about doing medicine and I didn't know what I was going to do. I was quite good at maths and sciences and so I decided to do a maths degree, I thought it left a lot of options open. I very much enjoyed maths, I even did postgraduate work in maths, but then I thought "There's got to be more to life than this", but I didn't know what to do. So I spent a few years in the wilderness, so to speak. I did voluntary work in India, I worked in the civil service, I was an actor for a while, all of the time thinking "What am I going to do with my life?" I always knew that I wanted to do something that felt worthwhile, that made a valid contribution to society. That was absolutely core but I could never find something that just ticked all the boxes and felt, right until I was probably honest enough with myself that in addition to all those worthy ends, I probably also wanted a decent income as well. I had to be honest enough with myself to accept that and then when I did, I thought that medicine ticks those boxes. (Daniel, respiratory)*

In describing their motives of helping people or doing good, the doctors did not really expand on what they meant by those terms. For one, it was about communicating well, for another it was about understanding all the factors leading to the patients' perceptions of illness and for a third it was to help people feel better. For the rest it was a concept, that it just felt the right thing to do, in other words an altruistic act [43].

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[43] Altruistic: selfless concern for the well-being of others (Soanes, C. and Stevenson, A. (2008) *Concise Oxford English dictionary*. 11th ed., rev.. edn. Oxford, New York: Oxford University Press.)

8.1.1.4 Fixing things

Amongst the respiratory physicians, there were also doctors who acknowledged that they were motivated by a wish to help patients get better from their illness. For example, having no personal connections with medicine, Jamie relied on television to give her an insight into what being a doctor actually involved, even if what she viewed was both American and fictional. She was inspired by the doctors' abilities to use their knowledge and skills to resolve the clinical problems that they encountered.

> *A: I think I just fell into it. Basically I enjoyed school and I was good at sciences and fell into it that way. I really liked watching medical things on TV and I just remember studying for my GCSEs and my A levels and the only thing that would bring me away from my work was that ER*[44] *came on on a Wednesday night. And I saw the people in the programme and I just wanted to be like them. So it was just TV predominantly, it was TV …*
> *Q: So let's go back to the values of being a doctor as you saw it. You watched it on ER. What was it about doctoring that made you think "I'd like to be one of them"?*
> *A: I just liked how professional they were. And I looked at the role models in ER, they were professional, they were knowledgeable. If there was a problem you could use your knowledge to fix it. And that attracted me. (Jamie, respiratory)*

I have suggested that the idea of medicine as a vocation can be understood in a number of ways, but that in all of them, the person describing their memories was driven by a desire to become a doctor. Some expressed a moral and emotional commitment to care, some to help in the Global South and some to help people resolve their medical problems. As I have indicated, all of the palliative and the majority of respiratory physicians expressed some of these motives. However a few of the latter did not appear to be driven by a vocation, and almost seemed perplexed that they had found what was for them, ultimately the perfect occupation. The participant just quoted alluded to her surprise, when she stated that she 'just fell into it', although she then justified her choice through the actions of George Clooney. The next section explores this in more detail.

8.1.2 A leap of faith

There seemed to be a cluster of characteristics which described this group of doctors and their perceived motivations. Firstly there was their apparent surprise at having found a university course and subsequent career, that they really enjoyed. This was evidenced by

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[44] ER (Emergency Room): US television medical drama starring George Clooney

their use of phrases such as ‘fell into’ and ‘leap of faith’. The second feature, perhaps explaining their surprise, was that they tended to come from families with no medical or nursing background, and the majority in fact described themselves as being the first in the family to attend university. Thirdly, they had been identified as being academically gifted at school, particularly in science and finally they interpreted their situation in terms of medicine being a career with a wide range of potential opportunities, which could suit all types of personal attributes. In this first example, Rebecca illustrates the whole cluster.

> *Q: Can I start by asking how you came to study medicine in the first place?*
> *A: I think I sort of stumbled into medicine rather than planned it from a long way off. There was no medics in my family, none of that kind of build up. It was just the idea that I was bright, I didn't go to private school, so people said "You know, you could do medicine." So it wasn't till I went to 6th form, that people said “you could do medicine,” and I sort of chose A levels on that basis, and it wasn't until I was applying to university that I said "I might apply for medicine and see what happens." I did a bit of work experience which didn't go very well, but I still thought "I'll give it a go." My entire approach was that I'd give it a try. And really I got in, started doing medicine and never looked back. (Rebecca, respiratory)*

It should be noted that during her work experience, she had repeatedly fainted at the sight of blood, but that despite this, she still pursued medicine with eventual success. Later on she described the absolute need for academic and learning ability, and how medicine could accommodate, and indeed needed people with a range of ‘skill sets’.

> *One of the things that I think, I think medicine is attractive because there is a place for lots of people in it. So I think you can find your place. To get through medicine and continue to thrive you do really have to have academic ability because you've just got to be able to take in a lot of information. You've got to meet deadlines and that's what the academic test is, there is that bar. For some people interpersonal skills and the caring side is the majority of their job, and the analytical and diagnostics is not part of it. For others it really is, but I think people find their natural place. If you look at the skill set that a pathologist needs it's completely different from a general surgeon. And so we should actually be very open. So it's difficult to say to 18 or 19 year olds "You're the right skill set" because in fact we need all sorts.*
> *Q: And what would you say your skill set is?*
> *A: I'm a real team player I think. I think I am ... I understand other people's point of view very easily.*
> *Q: Empathic?*
> *A: Empathic, that's the word, yes I think I'm very empathetic. And that works in terms of patients, seeing things from their point of view, and that plays into just understanding the team. So I make teams work, I think. (Rebecca, respiratory)*

Another respiratory physician, the son of two ‘manual workers’, had been identified by his teachers as bright enough to study medicine, although he himself played it down. Like Rebecca, William eventually found his own role in medicine, which he discovered, suited himself.

> *Q: How did you come to do medicine in the first place?*
> *A: Nobody in my family had gone to university, let alone done medicine. I was reasonably bright, but not the brightest kid at school. My teachers said "You're quite bright, you should do medicine." But I really didn't know what I was letting myself in for. It seemed vaguely interesting and* (there were) *external influences, but not from my parents, who were manual workers. I think I was probably about 15 when I decided, during O levels, when I was emerging from teenage anxt. I did A levels in the three sciences, although I was probably good across the board, I was probably stronger in geography and English though biology was definitely the easiest for me, which seemed intuitive. I was by no means the brightest kid.*
> *Q: Had you any idea beforehand what being a medical student or doctor would be like?*
> *A: No, it was a complete leap of faith. I was just convinced that medicine was so big that I would find a niche for me, and now I think I've found it. (William, respiratory)*

In the final example that is quoted, Joseph sounded somewhat perplexed that he had ended up studying medicine. Despite saying that it had not been ‘a calling’, he did describe some suggestion of having vocational motives, even if he was embarrassed to admit to them.

> *Q: How did you come to study medicine in the first place?*
> *A: To be honest, I didn't always want to do it. But I seemed to be doing OK at school and I almost fell into it. People said “you'd get the grades for that if wou wanted to do that”, and the more I thought about, the more it seemed like a rewarding job. And I did a bit of work experience and enjoyed it and kind of went from there. It'll be that whole corny thing of wanting to try and help people, I guess. Even then it wasn't a calling or anything, just something I fell into initially.*
> *Q: Did you know anybody to give you insight into it?*
> *A: No, I was the first person in our family to go to university. Once it was on the cards and I was thinking about it, towards GCSEs, I then went and got some work experience, but that wasn't through anybody, that was just me approaching the hospitals. And after the work experience I came away thinking "This looks brilliant, it's absolutely great" and it became the thing that I definitely wanted to do. (Joseph, respiratory)*

It seems clear that from their accounts these three doctors have found careers in medicine that they find fulfilling. This occurred in the absence of any medical pedigree in the family, and without much idea of what a career in medicine involved. Despite this, they had flourished in in the medical environment, and subsequently chose respiratory medicine. The final participant Joshua, quoted next in this section, also ‘fell into’ medicine, but although he shared all of the other characteristics that I have just described, he had another motive as well, which was to be successful and seen as a high achiever. He perceived that a career in medicine would help him fulfill these desires and expectations. What he did not express was any evidence of altruism.

> *A: To be truthful, I always wanted to do maths. Maths is what I loved, pure maths, theoretical maths. And then I was applying for university and one of my friends said he was going to do medicine and I thought "That sounds good, that sounds better than maths." So I thought I'll apply to do that. So I kind of fell into it because my friend was doing it and it sounded interesting and better than what my default position was … The other thing was "what I could do with a maths degree?" I don't think that schools were very good at saying "with maths you could be a banking analyst in London, you could be ..." when I was talking about it they said "You could be a quantity surveyor," which to me wasn't where I wanted to get to. I think for my school medicine was a glittering achievement almost. It was probably that he* (my friend) *was doing something better than me.*
> *Q: What in your mind's eye was 'better' about it?*
> *A: At that stage I probably didn't have a real understanding other than in the school it was perceived that doing medicine was a really high accolade and achievement and I'm someone who likes to win and do well.*
> *Q: Status?*
> *A: Yeah, maybe. Just that being successful was doing medicine. If I came through school and I got in to do medicine that was a real big win. And I think I am intrinsically motivated by doing good.*
> *Q: Doing good as in society?*
> *A: Doing good as in personally achieving a high level. It was probably for me more personal than for the good of society. (Joshua, respiratory)*

These quotations have illustrated a number of common characteristics between the participants. They all perceived that they were intelectually gifted at school, and all had attended state schools. None came from medical backgrounds, and it appeared that at the time of their decision to study medicine, they did not have much of an idea of what it actually involved. Despite this, they persevered, in the belief that there were enough opportunities within medicine (in its broadest sense) to satisfy their professional needs. In itself, this observation is not hugely surprising, what is interesting is that none of the palliative physicians expressed these views, but were all driven, at least in part, by vocational motives that they held before entering medical school.

The other point that is important to make at this stage is that although these participants did not appear to express much in the way of altruistic or vocational motivation for entering medicine, in these quotations, they did develop them. Later in their interviews, in describing aspects of the job that they enjoyed, all described variations on the theme of helping people. They just didn't realise it when they were making the intial decision.

The other important driver for the last participant that I have quoted, was the status that being a doctor would give him, one of the perks of the job, which is the final theme of this section.

8.1.3 Perks of the job

Apart from the themes already described, I have also illustrated two other aspects of a career in medicine that appealed to the doctors that I interviewed, namely a good salary (Daniel) and status (Joshua). In this section I shall explore this a little further, although in total only four participants expressed such views, including the two already quoted.

Christopher reflected on his adolescent decision to study medicine and appeared to be unsure of his true motives other than that he felt he needed ‘affirmation and positive feedback’ in his chosen occupation. Despite his apparently suspect initial motives, he subsequently became a successful and caring palliative medicine physician.

> *My aunt was a doctor but lived 200 miles away ... I think my reason was I thought I knew I wanted to be a doctor, but I couldn't explain to you what that actually meant. I think I thought that doctors made people better and made them feel good and I suspect that in retrospect it was all to do with people telling me I was good at something. That would have been one of the main drivers for me thinking I wanted to be a doctor, because then people would tell me what a great guy I was. A job that gives you respect, affirmation and positive feedback - yeh. (Christopher, palliative)*

In both the previous, and the next quotation, the role model who inspired the participants with respect was a visiting GP. In the first example this was Christopher’s aunt, and in the second it was the GP attending to Kevin’s dying relatives.

> *Q: Can I start by asking how you came to study medicine in the first place?*
> *A: I was always interested in sciences and I remember when I was in the third or fourth form, a couple of elderly relatives who had nowhere else to go, who died in our home. I remember finding the whole doctor visiting thing fascinating. I kind of decided I probably wanted to do it then. I vacillated a little bit, I got interested in pure mathematics but I never got rid of it completely so by the time I got to the upper 6th, that's what I wanted to do.*
> *Q: What was it about these GPs visiting that impressed you?*
> *A: When they arrived it was a bit of a performance, the fact that there was automatic respect, a bit of an aura about them was not unattractive at that age either. The ones I remember were nice practical people who were there to do something which struck me as intrinsically good, and did it well. (Kevin, respiratory)*

Apart from admiring the visiting GP's aura, this participant was also able to appreciate the beneficial contribution that the doctor was making towards his family members. As well as entering a career that demanded respect, he also valued the opportunity making a positive contribution to someone's wellbeing.

It is worth noting that, of the participants who said that they valued the status, security or salary that a career in medicine offered, all were male. As I have also shown, both specialties were represented amongst this group.

8.1.4 Discussion: personal characteristics

I have identified and illustrated three themes which I believe encapsulate the perceptions of these doctors, as to why they chose a career in medicine. It is apparent that there are similarities and differences between the principal motivational factors amongst the participants. The question I intend to explore is whether any differences expressed have any relevance to their subsequent choice of specialty.

The majority of the doctors that I interviewed have described some sort of a vocational wish as being their principal motivation to enter medicine. As I have indicated, the notion of a vocation implies both a sense of duty to perform, and and an aptitude for that role. In other words, in the context of medicine, the participants felt bound to help people and were (or became) good at it. Different doctors expressed different interpretations of what this might mean and in part this did influence their choice of specialty. The use of the word 'care' was almost exclusively restricted to those who became palliative medicine specialists. When talking about their experiences, some participants specifically described the physical act of personal care, as in mutual grooming (Jessica) or holding hands and offering a drink (Heather). For these and others, caring also involved a two-way relationship with the other person, including communication and shared emotions (Noddings, 2003; Downie and Llewellyn, 2012; Gheaus, 2018). Finally caring was described at a conceptual level, as an attitude towards other people (Nicole). The participants' references to their visits to the Global South to do voluntary work illustrate both physical care, as already described, but also the more abstract ideas of 'doing good' and 'making a difference' (Christopher). Values such as these, along with 'helping people", were the most widely described motivators overall and were expressed by both palliative and respiratory physicians. They were sometimes expressed at an even more abstract level, such as ‘a valid contribution to society’ (Daniel). It appears to be the case that the personal (caring) motives cluster towards the palliative physicians, and this is their *orientation*. On the other hand, the respiratory physicians displayed a wider variety of motivators, which are more difficult to summarise. Whilst it is evident that both specialties share a vocational wish to help patients, I suggest that they demonstrate a different *orientation* towards what this means. The palliative physicians are principally experience *oriented*, whilst the respiratory physicians prefer an outcome *orientation*. By this I mean that the palliative care physicians are primarily concerned with their patient’s lived experience and how to improve it, whilst the respiratory physicians aim to treat whatever is treatable and thus improve their patients’ health status.

The ‘leap of faith’ theme is very familiar to me, as it is how I would have described my own entry into medicine more than fifty years ago, if I had been asked the question at that time. It stems from entering the profession with little understanding of its nature and nuances, but an open mind to its possibilities and opportunities. Although such a view was only expressed by the respiratory physicians in this study, it is unlikely to be peculiar to that specialty alone. One of the respiratory physicians had described his choice of medicine over surgery in the following terms.

> *So I applied for both central medical and surgical SHO rotations, so still both ways, quite happy to do either. But then the medicine one was interviewed first and I got that so I withdrew from the surgery. So that is probably the true reason why I did medicine. (Joshua, respiratory)*

He described how as a young doctor, he was not yet fixed on a single career pathway, he was still pleuripotential and he could now be a surgeon, rather than a physician. It is an interesting observation that few of these doctors had medical parents, and of those who did, none described them as being influential in their choice of career. In contrast, a number of the palliative medicine physicians had mentioned their mother and her role in helping them form their caring values and subsequent choice of medicine.

Only a small minority of the doctors admitted to being partly driven by the appeal of a respected and well paid profession. They were all men, but from both specialties.

The other characteristic of the participants that appeared to be relevant in their eventual choice of specialty was their attitude towards religious faith. It has been reported that palliative medicine physicians are more likely to describe a Christian faith (Seale, 2010). In this publication, Seale wrote that ‘specialists in palliative medicine are more likely to be Christian, white and report being ‘very or extremely religious’ than doctors in other specialties.’ (Seale, 2010: 680), and this seems to be supported in this study, although there were only 16 participants in each group. As I have indicated in the methodology chapter, fifteen of the palliative medicine physicians said that they were still influenced by their Christian faith, even though some were no longer actively practising it. In contrast, only three of the respiratory physicians acknowledged a Christian faith.

8.1.5 Summary

In describing their motives to study medicine, the members of the two specialties expressed the idea that their role as doctors would be to help people, and I have described this as their vocation. What they actually meant by helping people was however quite variable. Amongst the palliative care physicians, caring was an important component, and in general they viewed the helping process at a personal level. They were concerned with people’s experiences, and helping them improve them.

In contrast, the respiratory physicians expressed a more conceptual attitude towards the beneficence of medical practice, using terms such as ‘help people’ and ‘valid contribution to society’. At an individual level, the notion of ‘fixing it’ introduced another difference between them and the palliative physicians. This phrase describes the primary aim of the respiratory physician, which is to identify the problem (for example a disease process) and treat it, thereby fixing that problem. The way of achieving the outcome is predominantly through biomedicine as I have indicated in chapter 2.

In this section, I have introduced the idea that those destined to become palliative physicians described an *orientation* towards people and their experience of illness, whilst the potential respiratory physicians were primarily outcome *oriented*.

8.2 Good Medicine

In the literature review, I described the features of good medicine as seen from the perspectives of each specialty. There were common aspects, such as patient centred care, but some of the features were different. For instance, respiratory medicine views care from a biomedical, disease oriented perspective, whilst palliative medicine is primarily concerned with the patient’s experience of her illness and addresses it through a holistic approach, to include the psycho-social and spiritual components. In this section, I will explore, through the participants statements, how the views of the members of the two specialties were shaped by their experiences within their specialty.

8.2.1 Good respiratory medicine

For some of the respiratory physicians, the desire to enter that specialty arose during their student years and persisted thereafter. In this quotation, Daniel illustrates the notion of the doctor as an inspirational role model and a wonderful clinician. He shaped the future career of his student, who joined the specialty so that he could try to emulate his mentor’s skills.

> *Q: OK, lets go back to your clinical years at medical school, were there attachments that shine out to you as being inspiring and helped form you?*
> *A: Yes, in my final year, I was attached to a clinician* (names him), *whom I found utterly inspirational. He was an absolutely clear thinker, very bright man, brilliant physician, brilliant communicator with patients. He was one of the brightest fellows you could meet and yet he had the ability to communicate at any level with any patient. He could strike up an easy rapport with anyone no matter what their educational background was and he could explain things and make difficult concepts easy. Which suggested to me that he probably understood them. And I just thought "One day I would like to be like that," which is one of the reasons that I came into respiratory medicine. (Daniel, respiratory)*

In his description of the consultant who inspired him so much, Daniel gave insight into the attributes that he respected, and subsequently aspired to himself in his own clinical career. These included intelligence, clarity of thought and the ability to communicate with all types of people. These characteristics were in addition to him being a ‘brilliant physician’, which presumably meant that he was skilful at the diagnosis and treatment of patients with chest diseases.

In a similar vein, the most influential factor for William in his choice of specialty, was the respiratory medical team in general, its leaders in particular and the camaraderie that existed between the members of the team from the most senior to the most junior member.

> *Q: Do any of your clinical attachments as a student shine out to you as influential or formative?*
> *A: The respiratory one: that's why I'm doing respiratory medicine. I had no particular fascination with lungs, there's nothing intrinsic about lungs that excites me. The reason*

> *I did respiratory medicine is the people. I was on the big unit in* (main teaching hospital)*, and the teachers, the consultants, were inspirational. You kind of thought, they were clinically excellent, academically many of them were strong and they valued you. Even as a medical student you were part of the team. They were inclusive, they supported you and I thought "when I grow up I want to be like that." So as a medical student I thought "That's the thing for me," and I tested it out by doing the house job with the same firm and I thought "this is as good as I remember." And I made sure my first SHO*[45] *job when I moved to* (another hospital) *was respiratory 'cos I thought "I'm just going to check it's not just peculiar to* (the original hospital) *respiratory" and it wasn't. It was the same.*
> *Q: And that was the team rather than the subject matter? In both?*
> *A: Yeh, absolutely. As you become a bit more proficient, you understand the diseases, and they're not so abstract. So you start to love lungs a bit more. But absolutely in no sense did I go into respiratory because of the disease. It was the people, it was the team, it was the nurturing and sort of high standards they set for themselves, the team. And you thought "That's quality medicine." The professor of respiratory medicine, he could cut it clinically, he would do a ward round and say "Oh you missed this, did you not hear the crackle*[46] *there?" but also would be publishing and having PhD students. It felt this kind of hotbed of bright minds and good doctors and team work. But he would take you as a team, as a medical student as an F1*[47] *to the pub on Friday and buy you a pint. At the end of the house* (the six months that the team are together)*, round to the professor's house for strawberry daiquiris and cigars. It wasn't laddish, the women were just as much a part of that, it was just team ... (William, respiratory)*

William admitted that initially he had experienced no particular interest in respiratory medicine or its patients. He was impressed by what he perceived as the good medicine that his senior colleagues practised during his attachments to respiratory teams. The leaders were good as clinical doctors and bright as academics. Although they set high standards, they were supportive and inclusive towards their juniors and this extended outside of the hospital ward. As he came to understand the subject matter of the discipline, he developed an attraction to that as well.

Robert expressed a similarly positive attitude about his postgraduate and higher specialist training. He offered unqualified praise for the senior members of the respiratory teams and a sense of joy at being able to work with them.

> *A: I was just completely inspired by the people I worked with. I thought the consultants on the respiratory ward were magnificent and exceptional standard of care, wide variety of cases - a really interesting mixed caseload. Inspiring people, I just thought "this is for me."*

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[45] Senior House Officer. Post-registration training post, but before entering higher specialist training.

[46] Crackle: a sound heard in the lungs through a stethoscope, helps in the understanding of the underlying pathology

[47] F1: Foundation year 1 doctor, the first job after qualifying

> *Q: What was inspirational about them? Was it their knowledge, their logic, their communication skills ... what bits?*
> *A: I think it was the whole package, there were three of them and they were all very good. They were incredibly good with the patients but they also engendered a sense of fun on the ward, it wasn't like you've got to be austere and very serious on a medical ward. You can also have fun and that doesn't mean it's bad medicine, in fact in many ways it's good medicine and you work as a team. You get through the hard workload that way and in the process you teach a lot and see a wide variety of cases. And I just thought "this is great, this is what I want to do." (Robert, respiratory)*

These three quotations illustrate the characteristics that attracted the respiratory physicians to each other and to the specialty itself. Similar observations were made by other participamts. They described their perceptions of what constitutes the ’good’ within respiratory medicine. There was a sense of a cohesive medical team, led by inspirational, but inclusive consultants, all of whom were working hard together and supporting each other. Individually, these leaders had agile minds and good clinical skills as well as being able to communicate with ease at all levels. In this idealised world, it was a joy to be a member of the respiratory team. If it is accepted that no setting is always ideal, these accounts do illustrate how the positive relationships between the doctors did help form some of the values of good respiratory medicine that the participants expressed.

8.2.2 Respiratory debate

However, the respiratory physicians did not always agree about everything, as this next quotation illustrates.

> *Q: Let's change a bit now to talk about ethical dilemmas. Can you think of a clinical encounter that has had you thinking of the ethical issues involved?*
> *A: I think one that's recurrent and it's a well known theme is: Do or do you not give home oxygen to people who are still smoking? I think that's a genuinely difficult ethical dilemma. There are strong arguments either way. I, in common with most of the respiratory consultants in* (hospital A) *sit on one side of the fence and I know my perfectly good colleagues in* (hospital B) sit *on the other side of the fence. We've had debates about this and I absolutely get the fact that there is no easy solution to this and I don't know really what the right answer to that is. So it's about long term oxygen therapy (LTOT) for people who are still smoking. (Daniel, respiratory)*

The point of this quotation is not to explore the rights and wrongs of home oxygen prescription for current smokers, which was what Daniel had used as an illustration of an ethical dilemma, but to demonstrate that respiratory doctors do differ in opinion and engage in ethical debate when they feel it is important and necessary. It also illustrates that they respect each other for their differing opinions. This is somewhat different to the palliative medicine community and their treatment of dissenters to the anti-euthanasia lobby, who have considered themselves to have been ostracised by the mainstream (Ahmedzai, 2012; British Medical Journal, 2019; Davies, 2019).

8.2.3 Respiratory collegiality?

The quotation below illustrates the collegial relationship felt amongst respiratory physicians. In this context, collegiality describes ‘a friendly relationship between people who work together or do the same job.’ (*Cambridge English Dictionary*, 2020) and also ‘relating to or involving shared responsibility’ (Soanes and Stevenson, 2008). Rebecca described meeting a stranger at an international meeting where she was presenting a poster. The person had expressed the view that there is a particular mutual respect amongst the respiratory community. On reflection, Rebecca felt that she understood and belonged to that community.

> *Q: What were the features of respiratory that appealed to you? I'm sure you were asked this at the interview.*
> *A: When I was a house officer doing that job in* (hospital)*, I did a poster and went to the ERS* [48]*. I remember standing in front of this poster and somebody, I've no idea who it was, either a consultant or registrar, said "the most important thing you do here is to look around at these people. If you think you can work with these people for the next 30 years, this is the specialty for you. If you don't, go and find somewhere else." And that is sort of what I've done as I've gone round departments. I've sort of thought "these people are slightly oddball, I'm not sure I can work with these," and whenever I've done a respiratory job, I've thought "these people might also be a bit oddball but I think I can work with these people." And that's been the case in almost every respiratory department I've been to. I thought "I can work with these people, I get them."*
> *Q: So you get on with the respiratory community?*
> *A: Yeh. I mean there is this whole thing of "I think it." (Rebecca, respiratory)*

What does ‘I think respiratory” mean? It is clear that the respiratory doctors feel very positively about their specialty and its members, they understand each other’s values and actions. The range of medical encounters and clinical activities that they may engage in are

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[48] European Respiratory Society meeting. The ERS exists as the European equivalent of the BTS. It organises educational meetings and publishes consensus statements on clinical issues, but has no regulatory function.

described elsewhere (Joint Royal Colleges of Physicians Training Board, 2019b; Health Education England, 2020b), and this section has illustrated the powerful relationships that exist amongst members of the respiratory community. They value each other as individuals, they value the medical teams that work together clinically, and they value each other as members of the whole specialty in the UK and indeed abroad. Respiratory collegiality is thus characterised by the friendly relationships and shared responsibility that are included in the definitions of collegiality that are quoted at the beginning of this section. It is this, which defines the ‘good’ in respiratory medicine.

8.2.4 Good palliative medicine

Palliative medicine evolved as a specialty out of the hospice movement, which in turn was predominantly inspired by Cicely Saunders (Saunders, 2006; Hanks, 2010; Overy and Tansey, 2013; Clark, 2016). The hospice therefore forms the cornerstone of palliative medicine training, although experience in other environments such as acute hospitals and the community now forms part of the required training (Association for Palliative Medicine, 2019a; Joint Royal Colleges of Physicians Training Board, 2019a). In this section, the doctors described their experience of higher professional training. Although the aim of this section will be to examine relationships between the doctors, it will become apparent that the perceptions of the training experience differ from those for respiratory physicians.

Most of the palliative doctors said that they had enjoyed their training, although not without reservations. This first participant, who had only recently completed his training, described an apparently well-organised scheme, an approachable teaching lead and a variety of training environments.

> *Q: Tell me about that training*
> *A: It's a training I've really enjoyed. As trainees I feel we're very well protected, very well looked after in terms of our on calls ... We've got good links with our training director, everyone is attainable. And in terms of the clinical practice I enjoyed being able to learn a lot more about palliative medicine and see different regions and the way different parts do it. So going round you do find role models as you move round the various areas. I think you take elements of people's character, you see things done really well. You see some things done less well and it really helps form you as a professional doctor. (James, palliative)*

However, what was evident in the account of his training experience, was the ambivalence that James had expressed towards his supervisors. He did describe good attributes, but also ‘things done less well’. This was somewhat in contrast to the respiratory participants, who mostly expressed unquestioning support.   A similar attitude was expressed by another doctor, Kelly, who appeared to have found more negative attributes in her supervisors than positive.

> *A: I liked seeing the variety of settings and I liked seeing the differences in how people practice palliative medicine, because the benefit of training is you get to see all varieties of how people work and pick the bits: "Oh that's how I would like to do that" or "I wouldn't do that". It's not that they're bad at it, but not how I would do it. You get to pick the best bits of people and try and copy them.*
> *Q: So role models?*
> *A: Different aspects of different people. I probably had stronger views of ways I didn't want to work. (Kelly, palliative)*

These two participants were expressing the value of having choice, in that they both perceived aspects of their supervisors’ styles that they would wish to emulate, but also those that they would reject. In fact, none of the palliative physicians expressed unqualified support for their training, either because of the limitations of their trainers or because of a preference for one of the three working environments over another, as I have described earlier in chapter 3.

As well as describing the areas in his training that appealed to him, Christopher, quoted below, was also critical of both his supervisors and the approach of the hospice to what he saw as excessive attention to unnecessary detail. In some ways, his attitude was more in keeping with the pragmatic and problem-solving approach of the respiratory physicians. Having said that, his attraction to ethics and communication skills was very much in keeping with other values of his chosen specialty (Joint Royal Colleges of Physicians Training Board, 2019a).

> *Q: Out of the palliative medicine training what bits did you enjoy most or least?*
> *A: I most enjoyed dealing with patients, teaching - doing ethics teaching with the professor of medical ethics, doing some communication skills: initially learning, then teaching. I had a fantastic time helping to set up and run the hospital palliative team in the cancer centre, which mostly involved me trying to persuade my boss that he didn't ever need to come in, as we were fine thank you very much … The bits I enjoyed least were dragging around after a consultant in a hospice doing things I really didn't feel needed to be done. They just spent too much time doing things that were unnecessary.*
> *Q: Tests, you mean?*
> *A: Not necessarily tests, but full clerkings on people, systematic enquiries on people*

> *who are going to die within the next week. The too much detail thing and spending too much time talking over things when I thought we have a plan, we can get on and do something else now. (Christopher, palliative)*

If the recollections of the positive features of the clinical supervisors that I have just illustrated seem modest, there were others that were more fulsome in their praise. In the next quotation, Angela described the attachment during her training that had most appealed to her. The feature that was most attractive to her was that it was an integrated service containing the three elements described earlier, which were well coordinated, and therefore provided an effective service for its users.

> *Q: Which bit of your specialist training made most impression on you?*
> *A: I loved working in* (names a city) *because you could make a real difference. It was a very well set up service, you had the community, hospital and hospice and day hospice working together.* (The city) *is a small village really, and so the day sister would give you a nudge and say, "so-and-so is not looking too good, you'll need to look at them, they might a bed for two weeks, might need an overnight carer." There was a lot of pro-active planning. Because it was small enough, it was joined up and the MDTs* [49] *were all shared as well. So they were all at the MDT together so people all knew what was going on. That was down to* (consultant who had set up the service). *He was very far sighted, they won prizes for that in the early 90s. So that was great. (Angela, palliative)*

There are two other relevant points, her unreserved praise for her supervising consultant for his organisational skills, and the value of the MDT in coordinating care. Unlike most other medical specialties, palliative medicine places prime importance on the MDT and on its members' individual contributions to the holistic care of its patients (Doyle *et al.*, 1993; Doyle *et al.*, 1998). The doctors' descriptions of their hospice experiences during training describe variations on the holistic approach to care, but also offer some insight into the strengths and weaknesses of the hospice approach. The next participant had moved to another city to start his higher training in its hospice, and he was greatly impressed by the whole experience.

> *A: I thought the city was lovely, a lovely place to be ... I felt the hospice, compared to* (another hospice) *was really well organised.* (Senior Consultant) *kind of knew everything about everything, kind of stuff, and he would sit down and take a patient's history and you would just be … ahh … and he was an amazing teacher to be around. Kind of scary, he would pick you up on why you were prescribing stuff three times a day when it could be given twice a day. He was kind of autocratic and sat there, didn't seem*

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[49] Multi-disciplinary teams. In palliative medicine, these might contain doctor, nurse, social worker, physiotherapist and other relevant healthcare workers, so they are actually multi-professional teams. In respiratory medicine, they contain doctors from different disciplines, such as respiratory medicine, oncology, radiology and pathology, as well as a respiratory nurse specialist.

> *to have a lot of fellow feeling for what was going on in the bed with the patient necessarily. But he recognised that, and he got a part-time psychiatrist in an NHS hospice on the back of him realising that the emotional side of him wasn't ... he couldn't pick up on all of these things. So it was useful to have a part-time psychiatrist there as well.*
> *Q: He knew the theory of holistic care but he couldn't do it all himself?*
> *A: Exactly, it was very much a team operation. And the time I was there* (a second consultant) *came to work with us. He'd come from oncology and was the complete opposite of* (the senior consultant)*, a gentle guy as opposed to* (the senior consultant's) *bang the table approach. They worked really well together. Then* (a third consultant) *came to work there, that was good, we started going out together. (Jason, palliative)*

It is clear that he had great respect for the senior consultant's positive attributes, including his diagnostic ability, theoretical knowledge and teaching skills. However, he was critical of his inter-personal skills, although the consultant himself was aware of his own limitations and addressed them with the appointment of a psychiatrist. The point is that his admiration of his mentor was tempered by disapproval. The other point that this quotation illustrates again, is the importance of holistic care in this environment.

In the interviews, it was apparent that different doctors expressed different preferences for their preferred working environment. The next extract is from one with a preference for hospital work, and in it, she describes her experiences throughout training.

> *Q: And now you are accredited, what are the features of this last 7 years that you've enjoyed best?*
> *A: ... mmm ... I think there have been aspects of all of the areas I've been in. Seeing how different teams do it. And I've enjoyed moving. I do remember feeling ready to move after being in a hospice for my first eight months and thinking "This is pretty intense ... like I'm ready to get out and see somewhere else." And I really enjoyed getting in to the hospital. I wanted to move on ... The hospices are funny places, they're wonderful places but sometimes they can be quite introspective and kind of "we do things because this is the way we do them here." They're quite intense places, both in terms of the turnover of the work and the emotional intensity. And I think working full time in a hospice is quite draining. I think I've always liked being in a hospital with other colleagues and I liked getting back into the hospital and being on the wards and advising. And working with a team of skilled nurses, because I'd not done that before, like closely. I definitely enjoyed the hospital placements and having not enjoyed GP in F2, I was a bit wary of community. But actually ended up really enjoying that too and having the freedom to get out and see people in their own homes and see how they really are rather than how they present themselves in clinic. (Michelle, palliative)*

In referring to the intensity of the hospice atmosphere, Michelle described the essence of its philosophy, which is characterised by close and reflective relationships, both between staff and patients but also between members of staff, exploring the meanings of emotions, symptoms and suffering (Saunders, 2006). It is evident that this environment was not suited to Michelle's own skill set, hence her preference for hospital and, to her surprise, the community. Of note was her mention of the importance of relationships with nurses during her training, however she made no reference to the importance of the other doctors in the hospice.

Perhaps unsurprisingly, those whose secondary qualification was in general practice [50] tended to express a preference for community work. Jason described how as a GP, he first came into contact with a member of a specialist palliative care service, in the form of a Macmillan nurse. This turned out to be a decisive moment in his choice of career.

> *And I had the opportunity down there to do a locum in the local Hospice at Home. I'd been looking after this lass at home in general practice who was vomiting, and I tried* (names a drug)*, and couldn't get the vomiting under control. This Macmillan nurse appeared and put up a syringe driver and I'd never seen one of those before, so I thought "I don't know much about this." And I thought that the four month locum in the Hospice at Home would be good and I just got completely hooked on it. (Jason, palliative)*

In the next quotation, Amanda also described her first experience of palliative care. She was a trainee GP at the time, and it illustrates a number of points which resonate with Saunders own motives for her choice of specialty (Saunders, 2006). She felt drawn to help people who were dying and she had also observed that the other doctors (in this instance her GP colleagues) had no interest in the problem. The third point is that she learned her initial skills from the nurses that she worked with, just as Saunders had done at St Luke's and St Joseph's hospices (du Boulay and Rankin, 2007).

> *That was because, based in the same health centre, were the Macmillan nurses and I discovered that I enjoyed looking after people who were coming to the end of their life.*
> *Q: Was that the job where you first come across such people?*
> *A: Yes, The other GPs weren't at all interested in looking after people who were dying, so I seemed to take it all on and worked very closely with the Macmillan nurses and discovered it was something that appealed. I would pick up the people who were more poorly and I felt able to give them the time that they needed and the attention. I would invest the time going back regularly and making sure people had the best care, I suppose. (Amanda, palliative)*

A number of conclusions can be made from the palliative medicine physicians' descriptions and comments about their training. Firstly, perhaps unsurprisingly, doctors expressed differing degrees of enthusiasm for the three training environments and this was evident in their final choice of work. Generally, those with a GP background preferred the community

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[50] MRCGP: Member of the Royal College of General Practitioners

and those with core training in hospital medicine [51] preferred that environment. Secondly, whilst the doctors described some positive attributes that they saw in their training consultants, they expressed reservations about them as well. Some of the participants described how they valued being able to select those attributes that they perceived were attractive, and reject the less appealing. In contrast, all of the doctors viewed the specialist nurses, such as Macmillan nurses, very positively, both as colleagues and as sources of expertise and learning. These observations point to the notion of the palliative care doctor operating within a multi-professional team, rather than the traditional ward based medical team that exists in hospital medicine and was described in this chapter by the respiratory physicians (Royal College of Physicians, 2019e).

8.2.5 Good medicine: conclusion

There are some differences between how the members of each of the two specialities view and respect other members of their own specialty and this gives an insight into how they view good medical practice. The attitude of the respiratory physicians, as expressed in their quotations seemed quite straight forward, they appeared to offer unreserved respect and support for each other and for their seniors and supervisors during training. In the previous chapter, I noted that the palliative physicians drew on ethical theory and deliberation readily in their daily work and that this formed a significant element of their notion of 'good medicine'. The respiratory physicians' clear respect for their seniors during training suggests that their notion of 'good medicine' was strongly influenced by these individuals, rather in the way that Gillon described during his own training, as I quoted in Chapter 2 (Gillon, 1985). The attitude of the palliative physicians seems more nuanced. Whilst they expressed a degree of affirmation and respect, it was often with reservation. These differences reflect the way in which the specialties work. The respiratory medical team tends to mirror the medical 'firm' that used to exist before shift work diluted individual patient care. In the days of the 'firm', a group of doctors: consultant, registrar, senior house officer (SHO) and house officer would have care for a group of patients. They would provide cover at all times, and would have an intimate knowledge of their patients and their problems. In the current system, when there is a shift system for out of hours cover, the weekly day-to-day care,

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[51] MRCP: Member of the Royal College of Physicians

which involves most of the communication and decision making is in the hands of the attending medical team, so the spirit of the 'firm' is maintained. In palliative medicine, the hospice team is multi-professional, and will include the consultant, a junior doctor, lead nurse, social worker, physiotherapist, chaplain and a variable number of other relevant health professionals. The *orientation* is thus towards holistic care and the potential collegiality of the doctors is diluted down by the other professional groups.

In simple terms, the respiratory physicians' statements about their training illustrated one aspect of the specialty's notion of 'good care'. They described a hierarchical medical team, led by the knowledgeable and wise physician, which offered care using a biomedical model of disease. At a wider level, the members of the specialty exhibit collegiality in terms of mutual respect towards, and understanding of each other. Good palliative medicine however, encompassed more than a medical model, and other disciplines were seen to be of equal importance in the multiprofessional team's aim to provide holistic care. It is possible that this led the consultants holding a lesser status in the trainees' eyes as decision-making was more of a team process. This summary exposes a paradox in relation to the specialties' professional societies. The BTS is a multiprofessional society for all involved in respiratory healthcare (doctors, nurses, physiotherapists, scientists), but the APM was initiated as an organisation for doctors, and has only recently introduced a membership category (Associate Member – Non Doctor) for other healthcare professionals (Association for Palliative Medicine, 2019a; British Thoracic Society, 2019). I will examine the potential relevance of this later

In the final section of this chapter, I will explore the palliative medicine physicians' views on their specialty's attitudes towards, and guidance about assisted dying. This has been primarily delivered by the APM. As I have already indicated in the literature review, palliative medicine is the only medical specialty to offer its members advice about the issue, and at the time of the interviews the RCP had not yet decided to ballot its members. For this reason the respiratory physicians had no organisational attitude to comment on.

8.3 Palliative Medicine, the APM and Assisted Dying

In chapter 2, I reviewed the history of the specialty of palliative medicine and the formation of the APM as its specialist society. I also described the APM's opposition to assisted dying and how it could be traced back to palliative medicine's origins. Furthermore, in chapters 6 and 7, I illustrated the palliative physicians' individual attitudes towards assisted dying, which were broadly in line with their representative bodies, namely opposition to any legitimisation to allow it.

As the majority of palliative medicine physicians did share the same general views on the morality of assisted dying as the APM, it might be expected that they would value and welcome the output of that organisation on the issue. In this section, I shall explore the palliative medicine participants' views on the APM's actions.

Just under half of the participants did indeed express satisfaction at the activities of the APM in relation to the assisted dying debate. In this first extract, Michael described his own lack of confidence in his ability to express his own thoughts on the issue adequately. He was reassured by the knowledge that others thought the same way, and that they could also present a more structured supporting argument. He also indicated his deference to the spokespeople of the APM.

> *Q: OK … the APM are quite active on this, do you find that helpful?*
> *A: (pauses) ... yeass ... I think, to me it's important to know that there are other people behind me in saying all these things. I think that there's something that reassures me that I'm not … I can't be completely wrong … if other great and good sort of people and organisations are supporting. But equally there are people who see it entirely differently to me … er … If I was standing up on my own I think I'd be less able to … erm … argue the situation*
> *Q: So it's a bit of back up for you?*
> *A: Back up, but also ... I don't know ... the intellectual arguments I can follow when I'm reading them ... but there's something much more emotional I think in me, about the arguments than pragmatic and rationalised I think that there is something that is quite deep that stops you from accepting this is the right thing forward and that's hard to really I mean it's there but its hard to identify what it is. And that's why I say that some of this is imprinted almost from an early stage. (Michael, palliative)*

He seemed almost apologetic at his own opinion and it seems as if he felt that he needed the APM to justify and validate it by articulating the arguments for him. As he implied, his childhood faith had left its legacy and he felt he needed up to date arguments to back this up. The next quotation is more revealing about the relationship between underlying values and the influence of the palliative medicine community. In addition to supporting the APM's stance, James described how his experience in training had reinforced his pre-existing values. It is interesting to note how he had assimilated both Cicely Saunders' values and the

APM messages about the issues into his own narrative (Clark, 1998; Clark, 1999; Saunders, 2006; Association for Palliative Medicine, 2019b).

> *Q: The APM have been quite active in their advice and guidance on this, do you find it helpful?*
> *A: I do find it helpful having the backing of the APM stance on the matter. It is in line with my views on it as well. So knowing that my personal views are reaffirmed by a professional body is helpful support.*
> *Q: Do you think your training has, sort of, taught you your views, or do you think your views developed within yourself?*
> *A: I think my views developed within myself, and have been shaped by my training. And my training has also taught me that people are less aware of palliative care as a specialty and I do wonder if: if half the people who are campaigning for assisted dying knew the extent of what is achievable with good palliative and end of life care, whether their views on the matter would be changed on the matter. It seems that there is a lot more publicised around the pro-assisted dying groups than there is anything on the anti-assisted dying. So much of the things that you read round dignity and choice relate to assisted dying. You can get dignity and choice within palliative care at the end of life. They're not something that can only be afforded to you by assisted dying. (James, palliative)*

Despite the fact that the great majority of the palliative medicine physicians held the same views as the APM, less than half expressed unqualified support for the conduct of that organisation. The next doctor, Nicole, while holding the same opinion as the APM, felt that she did not need its orchestrated guidance when she was called upon to express an opinion as she was capable of articulating her opinions herself (Association for Palliative Medicine, 2019b).

> *Q: I'm sure you know that the APM are fairly active in the assisted dying debate, do you find that helpful?*
> *A: Not particularly ...* (laughs) *... I sort of think if they changed to say they supported it, it wouldn't change my view. It's just not helpful, they send out prompts but it comes out naturally with the person you're talking to and I sometimes find having ... I find it hard to be scripted. And what comes out is very individual to the patient, isn't it? I rarely have the same conversation twice. (Nicole, palliative)*

Similarly, Matthew, who was also opposed to assisted dying, felt that the APM’s attitude indicated a vulnerability within the organisation in the face of changes in the attitudes of society as a whole. He perceived that the APM would not want any change in its members’ views in support of assisted dying to become apparent to the wider public.

> *Q: The APM have been quite active on this issue, is their advice helpful?*
> *A: I think it is, but I think they're almost behaving as though their position is under threat. And they're becoming more loud and extreme in the face of that and so there's*

> *been some discussion about whether there should be a regular vote within the APM about people's stance on euthanasia and it's certainly been vetoed for the moment by senior management. And that would muddy the water. So I think they don't think there will be a majority yet in favour of euthanasia but even just seeing a change in the proportion would be a bad PR. Whereas I think you can't really fight the tide of opinion, you have to work out how to cope. (Matthew, palliative)*

Other participants were more overtly critical of the stance taken by members of the palliative medicine community whether or not they held the same views. In the next extract, Michelle reflected on the attitudes and opinions of both the APM as an organisation and some of its individual members in relation to physician assisted suicide (PAS) debates. The point she made was that although she, and the majority of other palliative medicine doctors in the UK, are opposed to PAS, there are also people with an alternative opinion. She believed that their opinion should be respected in the discussions about the issue.

> *I guess in general, I mean I know there are members of the APM who would support PAS, but in general they don't, and I am of that stance. So I think I would be grateful of their support. And I think it's important that if as a body that's what the majority of members feel then that should be presented. And I think that's right.* (but) *I think it's important for any organisation to be able to openly discuss why they feel that way and to be able to openly debate that rather than just say that it is what it is. You know I think that engaging in dialogue is really important about these matters. I don't know that they're necessarily very good at doing that. I don't have enough involvement with them to know about how they're trying to do that. I think I would say, sometimes some of the members are quite forceful in the way they present things. I remember going to* (a national meeting)*, I went to that one year, and an older member of the palliative medicine family, he's been around for a long time, came and presented about physician assisted suicide. As much as I am against a change in the law on euthanasia, the way that he presented was just so one sided, and it was the same side as me, but so one sided it made me really angry and I just thought: "That is an unhelpful thing for anybody". And I thought any talk has to recognise is that there are going to be different views in the room and you can't just bash people over the head with your views and almost present it as though they're stupid if they don't agree with you or they're somehow morally wrong if they don't agree with you. I think that's really unhelpful and you know I think it's never helpful to take extremes and not see the other side. You need to sit down and have careful discussions like these, sometimes to agree to disagree. But you've still got to work alongside people and try and do the best for your patients. But that's very much individuals within the APM rather than the whole APM. (Michelle, palliative)*

In a similar, but more measured vein, Jennifer described her attitude towards the APM's activities. Like Michelle, she held the same view on assisted dying as the APM, namely opposition towards a change in the law. However, her concern was that the APM's apparently intransigent attitude would diminish public respect for palliative doctors in general. Jennifer preferred to express her own feelings about assisted dying, just as Nicole had.

> *Q: The APM are active in this area as well, do you find that beneficial or helpful to have them behind you?*
> *A: ... I don't know ... I don't know whether, externally to the public that looks as a bit of a barrier to actually communicating. I'm not sure, I think is the answer. I worry about being seen as a militant body who are not listening, that worries me. I don't think the general public would have a clue about the APM really, but I worry about communication breaking down, people not getting what I would see as the options for palliative care because they've already pre-judged all palliative care clinicians based on what their organisation says. Because, again, what it comes down to for me is is about that individual in front of me communicating there, rather what my APM body says.*
> *Q: So its your own opinion and you don't need them to make a fuss as well*
> *A: By and large if we communicate well as palliative care clinicians, we can do it better than there being blanket statements above our heads saying "This is what we believe". I think it's better just to meet someone and then we can sort through what's possible. VERY nuanced all of this and I find the black and white really unhelpful. (Jennifer, palliative)*

The last four quotations, from doctors who held the same general attitude to assisted dying as the APM, illustrate a problem that that organisation has aquired. In trying to dictate its own concept of the 'good', it has distanced itself from its more moderate members, even though they share similar values.

The precarious position of palliative medicine doctors who do publicly support assisted dying was exposed in an anonymous letter to the BMJ in 2019 (British Medical Journal, 2019). In it, the five correspondents drew attention to the stifling of free speech by the APM and how when one doctor announced his change in attitude to support PAD (Ahmedzai, 2012), he was ostracised by his peers. The need for more open debate on assisted dying been supported by a previous president of the APM (Davies, 2019). The following quotation illustrates Christopher's [52] experience when he attempted to engage in an open discussion about the subject with one of the most senior and respected members of the palliative medicine community. He was one of the two palliative medicine participants in this study who held an open mind towards assisted dying.

> *Q: The APM are active in this area and give us advice on the issue, how do you feel about this?*

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[52] Christopher was not himself one of the ostracised clinicians

> *A: It's* (names three senior APM members), *and I love them all dearly and think they're all fantastic, and because of that I'm not irritated by it. I know that they have a game plan and that they are already setting up for a switch from "No, let's not have assisted suicide" to "It's a society choice, we're stepping aside from the discussion about the rightness and wrongness of it, but it should be completely divorced from palliative medicine". And so I'm quite cool with allowing them to run that in their own way. I just respect the fact that it's difficult and I'm not going to mess with them too much.*
> *Q: So they'll be accepting defeat?*
> *A: I don't know that they would regard it as defeat, more a tactical withdrawal. I think they might have to wait until* (eminent member of the specialty) *dies before they do that because otherwise ... I wouldn't be wanting to speak to* (the member) *about that. I tried once, it was an error. I tried to suggest there might be a different way to see it and it didn't go well. I remembered that I was was speaking to* (the member) *and that was a mistake. (Christopher, palliative)*

Apart from his own perceived error in trying to suggest an alternative approach to the euthanasia debate, Christopher outlined his understanding of the organisation's exit strategy form the argument if the legislation were to be changed at some stage in the future.

A criticism of the lack of consideration for other people's point of view is also expressed in the final quotation in this section. Angela was also concerned at palliative medicine's apparently superior attitude in clinical practice, that it could resolve difficult issues that other specialties could not. She perceived that this could alienate the specialty from those it was seeking to help.

> *Q: My last question is about the APM and their role in the anti-euthanasia debate. How do you feel about that?*
> *A: I think they're too polarised and don't give an objective or balanced view. This is my opinion. I don't think they're doing themselves as a profession any favours. I think it would be far better if they came out with a more honest ... because they're too much at odds with ... probably the majority of clinicians who deal with people with advanced incurable and progressive disorders. I think we're at odds as a community of palliative care clinicians with those other clinicians who are seeing the reality of the distress in a much more medical way and we're thinking that we can fix everything as a profession and we can't. I think we should drop that, say "we'll do our best, why don't you give it a go" and stuff like that instead of presenting ourselves as something better than we actually are. And I think it gets up the nose of our colleagues hugely, big time. To come in:* (Imitates a trumpet fanfare) *The palliative care team are here!! And we have the luxury of so much more time as well in terms of what is regarded as the norm for a period of assessment. So the patients are going to love us ... But that's my opinion. You know what it is: I think they're trying to be too protective and it's not our job to do. (Angela, palliative)*

Although fourteen of the sixteen palliative medicine consultants held the same attitude towards assisted dying as the APM does, many were critical of the way in which the organisation has positioned itself on the issue. As I have shown, palliative medicine and its physicians value ethical deliberation and discourse, and the more thoughtful participants quoted in this study have applied such deliberation to the APM and its actions. They perceive that in its attack on the proponents of assisted dying, the APM has ignored or trivialised any arguments that do not suit its own. It is interesting to note that Cicely Saunders had expressed the view that 'those of us that think that euthanasia is wrong have the right to say so' (Saunders, 1959: 61), but that the organisation which has adopted most of her values appears not to be able to accommodate an alternative view of assisted dying. It also appears that there is internal conflict within the specialty on the issue, although the senior officers of the APM have denied it in their response to the open letter. (British Medical Journal 2019; Lawrie *et al.*, 2019).

It is evident in some of the participants comments, and in the correspondence in the British Medical Journal from 2019 (British Medical Journal, 2019; Davies, 2019; Lawrie *et al.*, 2019), that there is some friction within palliative medicine. It seems that this relates to the way in which the executive members seek to enforce the message (about assisted dying), rather than the values underlying that message.

8.4 Influences: Summary

The majority of the physicians were motivated by intentions to help people, in other words, by a sense of duty, as was included in the definition of vocation (Proffitt, 2018). The palliative care doctors tended to express this in terms of caring, whilst the respiratory physicians were more oriented towards solving problems. I have also shown how more of the palliative physicians were influenced by a Christian faith, and this is discussed in more detail in chapter 6.

Within their own specialty, the respiratory physicians exhibited a strong sense of mutual medical identity. By this, I mean that they share the same sense of direction in terms of the conduct of their clinical care, and that they respect each other's contribution to the process. They are also comfortable with their own position in respiratory society. This was described in relation to the clinical teams that they worked in, but also within the specialty as a whole.

The impression was of a collective common aim, which was underpinned by the specialty's biomedical approach to disease management and the communitarian structure of the BTS in relation to defining and reinforcing 'good' practice (British Thoracic Society, 2019; British Thoracic Society, 2020).

It is interesting to note that whilst the respiratory MDTs are dominated by doctors of different specialties, the BTS is a society with a strong membership of nurses and physiotherapists, as well as respiratory physicians. In contrast palliative care MDTs are truly multiprofessional, but the membership of the APM is almost entirely medical. It is possible to speculate that the respiratory physicians have established a confident and dominant position at the head of their specialty, therefore including nurses and other healthcare professionals in their professional body does not represent a threat to their hegemony. On the other hand, palliative care accepts a multiprofessional approach to its activities and the dominance that the doctors crave is achieved within palliative medicine as a specialty and the APM as its specialist society.

In their reflections on training, the palliative physicians described the importance of the other professionals that they encountered, particularly the nurse specialists. They also valued variety in terms of the attributes of their teachers, and the experiences and environments that they worked in. The debates around assisted dying that have occupied the palliative medicine community for more than 30 years give an interesting insight into the organisation of the specialty. It is evident that communitarian values expressed by individuals from the specialty are an important component of why most of them do object to assisted dying. It also appears that in dictating 'the common good' (Kymlicka, 2002: 220) in relation to attitudes towards assisted dying, the APM is illustrating itself as a communitarian organisation with respect to that issue.

Chapter 9. Discussion

9.1 What this Study adds to the Knowledge.

Palliative medicine's opposition to assisted dying has been apparent ever since the specialty was recognised by the Royal College of Physicians (RCP), in 1987 (Hillier, 1988; Doyle *et al.*, 1993; Overy and Tansey, 2013). In fact, Cicely Saunders had first expressed her own opposition to it over sixty years ago (Saunders, 1959), and her attitude towards the issue did not waver at all over the following years (Saunders, 1992; Saunders, 1995; Saunders, 2003). I have noted previously the variety of attitudes that had been expressed by palliative medicine doctors working in those countries where some form of assisted dying has been legitimised. They ranged between acceptance and cooperation with assisted dying services, particularly in Belgium (Dierickx *et al.*, 2016; Bernheim and Raus, 2017), through ambivalence, to opposition, in countries where there had been no attempt to link assisted dying with palliative care services (Bittel *et al.*, 2002; Gerson *et al.*, 2020). A common theme within these publications, was the internal conflict that the doctors felt between their wishes to respect their patients' autonomous wishes and their underlying palliative values which encouraged them to help and accompany their patients on their final journey to a natural death (Bélanger *et al.*, 1919; Blaschke *et al.*, 2019; Gamondi *et al.*, 2019).

There is, however, only a limited literature comparing the attitudes towards assisted dying between different UK medical specialties. In this thesis, I am making a substantial new contribution to that literature, both in terms of the substantive topic, but also in providing a new analytical framework for exploring such issues. The stark contrast between the attitudes of UK palliative medicine physicians and the other UK physicians was highlighted in the 2019 RCP survey on the issue (Royal College of Physicians, 2019c; Royal College of Physicians, 2019a). In the literature review, I summarised the surveys conducted by Seale, and his observations that in the UK, palliative medicine physicians were much more strongly opposed to assisted dying than other physicians (Seale, 2009c; Seale, 2009b). In these quantitative studies, he also concluded that the palliative physicians were more likely to hold religious beliefs, and that strong religious belief was independently associated with opposition to assisted dying (Seale, 2009b; Seale, 2009c; Seale, 2010). These studies could be interpreted as indicating that the reason for palliative medicine's rejection of assisted dying was its doctors' faith-based values. However, this would be a superficial oversimplification of what is really a much more nuanced issue. Whilst there have been a few qualitative studies looking at individual groups of doctors' attitudes to assisted dying (Hussain and White, 2009; Blaschke *et al.*, 2019; Gamondi *et al.*, 2019; Gerson *et al.*, 2020), there have not been any comparative studies that might give insight into why palliative medicine seems to be such an outlier in the UK. By performing in-depth interviews with palliative medicine physicians and respiratory physicians, as exemplars of 'mainstream medicine', I have obtained a rich data set, which I have analysed to provide a clearer understanding of the relevant issues. Such a deep understanding could not have been achieved through a quantitative, questionnaire-based study. Through my analysis, I have been able to link the individual participants' values with those of their respective specialties. In doing so, I have demonstrated that there were some common values amongst them all, such as putting the patient first, and always acting within the law, and I have described these as *absolutes.* In contrast, there are also some consistent differences between the two specialties and their members. I have described these as the *orientation* of each specialty and I have illustrated these in relation to assisted dying and the notion of good medical care towards the end of a patient's life. I have further shown how for a particular issue, the *orientations* lie on a *spectrum,* and individual *orientations* lie on that *spectrum*. In doing this, I have provided an alternative and more nuanced update to Jewson's cosmologies of medicine, which were originally proposed in 1976, and the paper was re-published in 2009 (Jewson, N.D., 2009), as a way of interpreting the relationship between 'medical knowledge' and how doctors from these two specialties behave. In turn, this has enabled me to theorise about the identity and organisational structure of these two specialties, and how they may, or may not seek to influence their members in forming their opinions. The initial area of interest to me was care at the end of life and in particular, assisted dying. I shall now discuss the significance of my findings, and how they compare, contrast, and contribute to the existing literature.

9.2 End of Life Ethical Dilemmas

During the interviews, I explored three contentious issues relating to end-of-life care with the participants. These were when a competent patient either refused or asked for the withdrawal of life sustaining treatment, when life sustaining treatment was withdrawn in an incompetent patient's 'best interests' and how a request for assisted dying from a competent patient was handled. It was clear that the current state of the law in the UK was important in helping the participants form their views on all these three issues. I have already referred to the relevant landmark cases, such as *Re T* for the refusal of potentially life prolonging treatments by competent adults, and the case of Tony Bland for the withdrawal of similar interventions in an incompetent adult's 'best interests', in the literature review (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018).

All of the participants, who reflected on cases that they had been involved in where the patient requested the withdrawal of life prolonging treatment, supported that request. This included both respiratory and palliative physicians. What became apparent in their descriptions of the events, was that the palliative physicians appeared keen to justify these actions using descriptors like 'legal and ethical' (Michael) or 'in terms of ethics and the law … I felt very clear in that, and (it was important to) make sure that the nursing staff didn't think that we were euthanasing somebody' (Jessica). In contrast, the respiratory physicians, including Christina, Laura and Erin described their involvement in relatively matter of fact and unqualified terms, suggesting less introspection on their part. Despite this apparent lack of self-awareness, the actual descriptions of the process suggested that similar attention had been paid to appropriate moral conduct during the procedures by both specialties. This supports the notion that while the palliative physicians engaged more actively in moral deliberation and reflection than their respiratory counterparts, all the participants acted in an ethical manner in actual clinical practice. In chapter 8, I showed how the respiratory physicians developed their notions of good practice from working with their seniors and supervising consultants, rather than engaging in the ethical deliberation favoured by the palliative physicians. In other words, the palliative physicians expressed an *orientation* towards more overt ethical deliberation and discourse, whilst the respiratory physicians relied on the wisdom that they had acquired from their teachers during their training.

The participants' attitudes towards assisted dying largely mirrored the quantitative data that already exists and has been reported elsewhere. In Seale's study, 9% of palliative physicians accepted PAD in certain circumstances, against 39% of 'other physicians' for the same question. Similarly, in the RCP survey, opposition to a change in the law was expressed by 81% of palliative physicians, but only 48% respiratory physicians. (Seale, 2009b; Association for Palliative Medicine, 2019a; Royal College of Physicians, 2019a). In this study, fourteen of the sixteen palliative physicians that I interviewed were strongly opposed to assisted dying, the other two expressed tentative support, tinged with anxiety, for reasons which will be explored later in this discussion. There was a much wider range of attitudes amongst the respiratory physicians. Although the majority offered some degree of support for assisted dying for those people who wished it, they expressed some ambivalence about it as well. A few of these doctors were undecided, but only two expressed clear opposition.

It was apparent that the palliative doctors were well rehearsed in their deliberations about assisted dying and used well developed arguments to back up their views. These included the adverse effect that a change in the legislation would have on the relationship between the palliative medicine physicians and their patients (Matthew, Heather), and how people should be supported to 'die naturally', rather than seek an earlier (unnatural) death (Nicole, James). For instance, James said: 'what we're seeing is a natural process of dying and there's nothing that we should do to alter that.' Indeed, another palliative physician, Michelle had even written a letter to a leading British journal outlining the reasons for her opposition to assisted dying. In contrast, it seemed that most of the respiratory physicians had not given the issue much thought before coming to the interview, and they appeared to develop their opinions as they talked about it during the interview (Robert, Joseph, Joshua). William had summarised his own attitude towards assisted dying by saying that 'I'm happy to say I've buried my head in the sand about this. To some extent it's because it's something I won't be doing and actually on a day-to-day basis it isn't a clinical problem to me.' This statement encapsulates a (respiratory) view that the issue of assisted dying is not a big problem in day-to-day medical practice, so there is no point getting concerned about it. In contrast, the palliative physicians expressed an *orientation* towards active ethical deliberation about assisted dying and within this, opposition to it.

Beneath these attitudes towards assisted dying, two apparently conflicting underlying moral values [53] were expressed by the participants, to justify those attitudes. These were the sanctity of life and the importance of individual autonomy, and I shall explore these in more detail next.

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[53] Values: principles or standards of behaviour, considered to be important or beneficial Soanes, C. and Stevenson, A. (2008) *Concise Oxford English dictionary*. 11th ed., rev.. edn. Oxford, New York: Oxford University Press.

In setting the scene for his discussion of the legal aspects of the euthanasia debate, Herring refers to the idea that 'The heart of the debate' is the interplay between the sanctity of life and the respect for an individual's autonomous wishes (Herring, 2018: 543). My interpretation of the participants' reflections on the issue supports this view, although the participants deployed several other arguments as well, in support of their opinions. I have shown that there were different interpretations of the meaning of autonomy itself that were used on both sides of the argument by members of both specialties, as well as different perceptions regarding the intrinsic value of life.

9.2.1 Concepts of autonomy

In chapter 2 of my critical review of the literature, I described how interpretations of the meaning of autonomy lie on a *spectrum* dependent on the regard for the consequences of an autonomous person's act on others (Woods, 2005; Maclean, 2013; Christman, 2018). When discussing the patient's role in decision-making, the participants described autonomy from liberal, communitarian or relational viewpoints. The key to understanding Liberal autonomy is that whilst it entails freedom from external interference in individual decision-making, there must also be a commitment not to interfere with the choices of others (Woods, 2005; Woods, 2007; Gaus *et al.*, 2018). The two other relevant concepts of autonomy in this study were communitarian and relational. I have already described how a version of communitarianism dates to early Christianity, but it later arose as a moral counterpart to the liberal egalitarianism of the 1970s (Selznick, 1987; Etzioni, 1998; Rawls, 2005; Bell, 2016). A central and common approach within communitarianism is the claim that people are not 'isolated individuals', but members of the society that they live in. The implications of this are that both the individual and the community to which she belongs are held together by shared common interests, and that they have obligations towards each other. These interests include a respect for the structures of their community, such as the family as a unit, religious faith and valuing each other as people in their own right (Eberl, 2018). Relational autonomy focuses on the importance of the close relationships that form between people and that it is impossible to make decisions without acknowledging the influence of these relationships in the process (Kittay, 2001; Christman, 2004; Downie and Llewellyn, 2012).

In considering the responses of the participants, it was possible to see differences in their preferences for one interpretation over another. For instance, although the great majority of participants overall aspired to allowing ‘patient choice’ when describing their interactions with their patients, there were different interpretations of what this actually meant in practice. In this study, most of the respiratory physicians, such as Joshua, Brian, Ryan and Laura, used a liberal interpretation of autonomy in their support for assisted dying. For example, Laura said: ‘I think the main thing is that it's their responsibility and their choice, but also who are we to say: "You have to live on like you are in distress and pain, whether it's mental pain or physical pain and suffering”?’ This provides a clear example of the liberal approach towards patients who request an assisted death, which sits in stark contrast to the communitarian rejection of assisted dying that was widely expressed by the palliative physicians. These doctors, when describing real or imaginary requests for assistance to die, talked in terms of valuing their patients as people, or of protecting them as vulnerable members of their society. Michelle, Jason, Jessica, and Lisa all expressed these types of opinion. For example, Jason spoke in terms of being ‘a fellow human being’, and Amanda was concerned that ‘they might be influenced by other people or by their own desire not to be a burden’. It is possible to view this need of the palliative physicians to protect their patients from their own (misguided) desires as being paternalistic. Jennifer had recognised this (in theory), but she still said that ‘I've put her wishes before my wishes, but of course I want her to be in the safest place’, when discussing a patient’s wish to be discharged home in what she saw as risky circumstances. What Jennifer was actually doing was putting her own wishes (as proxy for the community that they belonged to) over those expressed by her patient.

Daniel (respiratory) and Matthew (palliative) both used relational autonomy to support their opposition. Matthew described how he felt that ‘even from a non-religious point of view families … and people being able to see through things, seeing grandchildren and so on is really important’. Several of the doctors from each specialty actually described relatives making comments such as “you wouldn’t treat a dog like this”, presumably implying that they believed that their suffering family member should have their life ended, even if they had not requested it themselves. An example of a palliative response to such an observation’ came from Michelle, when she replied, ‘We wouldn’t treat a dog like this, but that’s because you’re a human and you’re not a dog and I think the two are very different.’ In so doing, she was expressing her view of the sanctity of human life.

The *orientations* in in respect of autonomy that were expressed by the members of the two specialties have been seen to sit towards opposite ends of the *spectrum*. I have shown that most respiratory physicians were *oriented* towards liberal autonomy and supporting patient choice, whilst those from palliative medicine preferred to protect their patients as valued members of a family or a community. In this way, their communitarian *orientation* defined what was best for those patients.

9.2.2 Sanctity of life or not?

Just as there was a *spectrum* of views about autonomy, there were differing views on the value of human life as well. Most of the palliative physicians, including Michael, Jennifer, Jason, and Jessica believed in the sanctity of life from a Christian perspective. Some actually used the term, such as Amy, when she was justifying her position on assisted dying and she said that ‘I think, I personally do feel … I suppose it just goes back to that sanctity of life.’ Some, such as Nicole and Amanda, made comments suggesting that as human life was a gift (from God), it should not be taken away, even at that person’s request. Although most of these participants made such comments from a faith background, there were one or two, who held a similar opinion from a secular point of view. Melissa, who was not religious, was particularly influenced by the legal concept of the sanctity of life, when she said: ‘People don't kill and however ill people are, we don't kill … I think it's humanistic and legal: law of the land.’ The data from the palliative medicine physicians illustrates how, although the value of human life was seen from a few different perspectives, it was used in a similar way in their arguments to oppose assisted dying. These paralleled the communitarian arguments, in that the ‘good’ was defined by faith (or the community), rather than the individual requesting to have her life ended.

In contrast, although they clearly revered human life in general, it seemed that most of the respiratory physicians, such as Joshua and Ryan, felt that the final arbiter of the value of a particular life should be the person living it, rather than society, doctors or God. In his defence of individual autonomy, Joshua had said that: ‘There are clearly some people who are choosing in Europe or going to Dignitas, and who can say that that isn't the right decision for them. They are making an active choice, which presumably they understand that for them the life that they've got is worse than being dead'. Even those respiratory physicians who did hold a Christian faith shared this sort of attitude, suggesting that for them, respect for individual autonomy was more important than other notions of the sanctity of life.

Having said that, when it came to reflecting on their own potential role in the assisted dying process, there was an almost unanimous concern amongst the doctors from both specialties that they would not want to be involved. This is the subject of the next section.

9.2.3 Duties of a doctor

During the interviews, the participants reflected on their duties as doctors in general as well as in relation to assisted dying, if it were to be legalised. It was evident that actual requests for assisted dying were uncommon, so most of the discussion of doctors' potential involvement in assisted dying was in relation to a hypothetical situation. Despite this, it did engender some emotional responses from members of both groups of physicians. For example, both Laura and Brian (respiratory) had indicated their notional support for assisted dying, but when faced with a question about their own potential involvement in the process, they were very uneasy about it. For instance, Laura said that: 'I always thought it's their decision … The difficulty I have then is the question "Would you prescribe the drugs yourself?" … Would I prescribe the drug? I found myself thinking "Whoah".'

In general terms, most of the doctors saw their role as helping people (Christina, Joseph) and making their lives better (Jamie). However, their overall attitude was that doctors' duties should not include killing their patients themselves. Several participants traced this back to the Hippocratic Oath and others described how it was not what they had been trained to do (Michelle). Because the respiratory physicians generally favoured patient autonomy, discussions about assisted dying provoked considerable self-questioning about what a doctor's own role in the process should be, in the event of it being legalised (Joshua). Some concluded that it might be to help the patient to achieve what she wanted, even though the physician personally might have felt that it was not necessarily the best option. This raises questions about conflicts in values between doctors and their patients. Practicing patient centred care would presuppose an equal partnership in the decision-making process, given the proviso that patients cannot by law demand a 'medical treatment' if the doctor felt it to be inappropriate (Brazier and Cave, 2016; Laurie, 2016; Herring, 2018).

The palliative physicians, being innately opposed to assisted dying, viewed such potential requests in the light of what was best for the patient (in their view), in other words, a more paternalist approach towards the patient. This raises the question of who the expert is when it comes to assessing the nature of a person's suffering and the value of her life.

9.2.4 Summary

In this section, I have explored the attitudes and values of the respiratory and palliative physicians, when talking about assisted dying. I have shown some similarities and some differences between the members of the two groups, and I have described the differences as the *orientation* of each specialty and the similarities as *absolutes*. In their rejection of assisted dying, the palliative physicians' *orientation* was underpinned by beliefs in the sanctity of life, Christian faith, and a communitarian duty to protect the vulnerable in society. These doctors also placed importance in ethical deliberation and discourse in deciding a course of action. The tentative support for assisted dying that was expressed by most of the respiratory physicians, illustrates their *orientation* towards a liberal egalitarian approach, where individual choice was the dominant value. Neither religious faith nor overt ethical deliberation appeared to be relevant in helping them form their opinions. The great majority of the participants overall, felt that their duties as a doctor precluded them from any active involvement in euthanasia, whether or not they supported the concept in principle, and this was therefore an *absolute* value. As the participants reported during their interviews, requests for an assisted death were in fact uncommon in their experience of medical practice. Most of their clinical time would be spent engaged in the healthcare activities of their specialty and some of the respiratory physicians expressed the view that as assisted dying is illegal anyway, there would be no need to even think about it (Daniel, William). It is therefore important to understand how the members of each specialty viewed good healthcare in general, as this would be formative in their approach to the end-of-life issues that have just been discussing. I will explore this next.

9.3 Good Medicine

In this section, I will explore the two specialties' views on the nature of good medicine, as this is important in understanding how they developed their views on care for people at the end of their lives.

I have described how care can be thought of as describing an act, a relationship or the disposition of a person (Noddings, 2003). I have also described how, in describing their motives for studying medicine, the use of the word 'care' as a motive for taking up medicine as a career, was used solely by those destined to become palliative physicians (Nicole, Michael, Jessica), as exemplified by Jessica who said, 'I wanted to do good work and care for people'. The notion of care as a component of healthcare, holds a central place in palliative medicine, but is not evident in respiratory medicine. Of the three characteristics of care described above, the most widely expressed by the palliative doctors in their interviews was the importance of developing a close relationship with the patient (Jason, Jennifer) and this was also central to Cicely Saunders' view of the therapeutic relationship (Saunders, 2006). Within the caring relationship, a reciprocity develops, which involves duties and permissions for each party (Noddings, 2003; Gheaus, 2018; Norlock, 2019). This in turn requires an element of moral judgement, to do what is right, and was described by Michael, Jennifer, and Jason, amongst others. For instance, Jennifer described her relationship with a patient in the following terms: 'I can remember spending a lot of time with her and her dignity, with that horrible ... she was a very dignified person … and how her dignity was preserved in that context, was quite a beautiful thing and that had a big impact on me.'

Another feature of the 'good medicine' that the palliative physicians aspired to was to consider the patient's illness and suffering from all aspects, rather than merely the biomedical (disease centred) approach. The palliative physicians described holistic care repeatedly in their interviews, sometimes spelling out the 'bio-psychosocial and spiritual aspects' (James). Melissa, when describing what appealed to her most about her specialty, said that 'It just seemed to fit, and I loved it … I think mainly the holistic side, the time for the patient, so the time to ask about them, the time to find about their families, the time to actually pull it together'. Interestingly, the word 'holistic' was not used by the respiratory physicians at all, although at times they did refer to the non-biomedical aspects of their patients' illnesses and to their families.

At the other end of the healthcare *spectrum* is biomedicine and evidence-based medicine (EBM). As I have indicated, the principle of EBM is to apply a scientific approach to the study of diseases and their treatment (Sackett *et al.*, 1996; Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). In this way, statistical evidence of the efficacy of treatments can be obtained, and protocols and guidelines produced, based on meta-analyses of the trials of treatments. Respiratory medicine, through its specialist society, the British Thoracic Society (BTS), is a leading proponent of EBM in the UK (Woolhouse *et al.*, 2018; British Thoracic Society, 2020) and both Rebecca and Joshua described their preference for this approach. It is interesting to note Joshua's attitude to the lack of an evidence base in palliative medicine when he undertook a diploma in it, he said 'I think I went there looking for answers and the answers aren't there'. In theory, EBM offers the best treatment options for a particular medical condition and so helps doctors to practice 'good' medicine. It might also be said that it is value neutral, in that if a patient fulfils the pre-defined criteria, she should be offered the treatment and there is no need for further ethical reflection or justification. It might also be described as reductive because it narrows the field of focus for the doctor and excludes the ethically contentious elements. The question then arises as to whether the respiratory physicians were attracted to the specialty because it does not appear to require or demand the same degree of moral deliberation as was evident in the palliative physicians' reflections on their practice. Certainly, in chapter 7, I described how palliative physicians such as Jessica were attracted to discussions about medical ethics even as a medical student. On the other hand, Kimberley, and Joseph (respiratory) dismissed it as undergraduates. Likewise, the palliative physicians demonstrated a greater degree of moral introspection when describing similar challenging clinical interactions, such as the withdrawal of assisted ventilation, than their respiratory counterparts.

I have described the two directions of good medical care as indicators of what I see as the *orientations* of each specialty, but it appears that there is in fact considerable overlap between the specialties. For instance, one of Cicely Saunders' contributions to her specialty was a rigorous scientific approach towards the investigation and treatment of pain and other symptoms (Twycross, 1973; Saunders, 2006). Similarly, the respiratory physician Robert's description of his patient's choice to have her oxygen removed to allow her to die, indicated deep moral deliberation: 'very, very grateful for the patient. She could have made it very difficult for herself, she could have made it very difficult for me'. The palliative physicians, therefore, are principally *oriented* towards forming close caring relationships with their patients, having sufficient time to understand all the contributing factors affecting the patient's experience of illness, so that they can find a mutually acceptable solution. Another important aspect of their practice is to be able to reflect on the morality of their actions. Respiratory medicine adopts a framework underpinned by biomedicine and EBM, so that their main objective, which is cure or disease modification, can be achieved with some degree of predictability. However, as a significant part of their work is with patients with chronic and progressive disease, where the outcome is not predictable, they will also need to engage in value judgements about healthcare choices. When Christina (respiratory) was involved in the removal of assisted ventilation at the patient's request, she acted in an ethically appropriate manner towards her patient and his family. Although she seemed to have viewed the act as being less ethically exceptional than Jessica (palliative) did, her actions were no less morally appropriate. This raises a question of whether the intervention was just more familiar to the respiratory physician, and therefore more routine and less exceptional, which is certainly a possibility. The alternative, as I have proposed, and will explore further below is that respiratory physicians just do not engage in overt ethical deliberation to the same degree as the palliative physicians.

Another point about evidence-based medicine is that although the end point, the actual delivery of an intervention, may seem to be value neutral, it is not. The production of the guidance in the first place requires moral decisions about efficacy, side effects and cost (beneficence, non-maleficence, and justice). Similarly, for a given intervention, judgements must be made at an individual level (by the doctor and the patient) as to its appropriateness for that person at that time. Another relevant issue in relation to EBM and its use by each of the specialties is that it is relatively easy to adopt a scientific approach to disease treatment, but less so to the management of suffering. Although palliative medicine has made attempts to quantify symptoms, the very nature for instance, of 'total pain' (Saunders, 2006) renders it almost impossible to quantify it in a meaningful way. Similarly, using the multi-professional approach to the bio-psychosocial and spiritual aspects of suffering (in other words holistic care), would make it difficult to identify the relative efficacy of each component. In chapter 2, I discussed how some commentators saw EBM and holistic medicine as being incompatible with each other (Salmon and Berliner, 1980; Williams, 1998), whilst others saw them as compatible, but towards opposite ends of a spectrum (Patel, 1987; Frey *et al.*, 2013;

Greer and Joseph, 2016). My own preference, as I have indicated, is for the latter interpretation.

In chapter 7, I explored how the members of the two specialties approached ethically contentious practice, and also the importance that they attributed to ethical deliberation and discourse generally. I proposed that, from their accounts of similar clinical situations, they appeared to act in an equally moral fashion with their patients. However, I illustrated how ethical theory, deliberation and discussion were more important to the palliative physicians than to their respiratory counterparts. I have already described how such an *orientation* is evident at specialty level, in terms of the apparent importance that each specialty gives to ethical theory in their training programmes (Joint Royal Colleges of Physicians Training Board, 2020a; Joint Royal Colleges of Physicians Training Board, 2020b). All medical interventions involve some degree of internal ethical deliberation on the part of the doctor about the appropriateness of the proposed course of action, whatever the specialty. However, issues around the end of life, such as the appropriateness of actions that may prolong or shorten it, tend to provoke more moral consternation than when death is not on the horizon. This might explain palliative medicine's close attention to ethical issues, as the end of life forms a larger proportion of their workload. The apparent difference in attitude towards the importance of ethical deliberation between the two specialties raises the question of whether the palliative physicians are over-sensitive to such issues, or the respiratory physicians under-sensitive, or whether it matters at all. On the one hand, it might be argued that if the actual clinical interaction is appropriate then explicit moral reflection at the time is unnecessary, and indeed may actually delay decision-making in urgent situations. Certainly, the descriptions of the respiratory physicians' workload would tend to suggest that they did encounter such acute situations more frequently than the palliative physicians, who tended to speak of the importance of having adequate time with their patients to form the relationship and then reach a decision. On the other hand, as I have mentioned, both specialties do manage patients who are approaching the end of life, when a more reflective approach might be more appropriate. Certainly, in her own reflection on the interview, Crystal (respiratory) did contemplate whether she should be giving such thoughts more attention than she had done. This then raises the question of whether the respiratory curriculum should offer a more prominent position to medical ethics than it appears to at present. Another interpretation of respiratory medicine's apparent disinterest in ethical theory and discourse is that they acquired their medical values through another route entirely, which was by observing their wise supervisors during training. I illustrated such an attitude in chapter 8 when Daniel described his decision to become a respiratory physician in the following terms: ‘I was attached to a clinician … whom I found utterly inspirational … And I just thought "One day I would like to be like that”.’ This also resonates with Gillon’s quote from the last century when he wrote that ‘We learnt what was done and what was not done, mostly from the example of our teachers … We never heard about utilitarianism and deontological theories of ethics’ (Gillon, 1986: 29). I have, therefore proposed that on the *spectrum* of moral practice, the palliative physicians are *oriented* towards ethical theory, deliberation, and discussion, whilst the respiratory physicians value the learned experience of their wise and virtuous seniors.

As I indicated in chapter 6, the data suggested that both groups of physicians tried to help their patients in the different environments that they found them in, and that both supported a patient-centred approach to achieve this (Mead and Bower, 2000; Wirtz *et al.*, 2006). To achieve this, they follow different *orientations* in their approach to ‘good’ medical care. The palliative physicians are concerned with their patients’ suffering, and to understand this, they need to form close caring relationships with those patients. The care that they offer is based on an understanding of the underlying physical, emotional, social and spiritual elements of that suffering, so it is predominantly holistic, although they try to adopt a biomedical approach to symptom management. Because the main component of the respiratory physician’s workload is (respiratory) disease modification, the *orientation* is towards the control of those diseases and is therefore predominantly biomedical and evidence based. However, their patients are people, and relationships with them are important for the doctors so that they can help the patient achieve the desired outcome. The fact that patient autonomy was a dominant value for the respiratory physicians in the assisted dying debate confirms the importance that they put on understanding their patient's true wishes. This could only be achieved through developing a good and trusting relationship with them.

9.4 Influences

In the preceding paragraphs, I have proposed the characteristic *orientations* of the two specialties. I have discussed how they apply to 'good' healthcare in general and towards end-of-life care, with particular reference to assisted dying. I have suggested that the palliative physicians expressed their opposition towards assisted dying through communitarian and faith-based interpretations of the sanctity of life. In contrast, the respiratory physicians' tentative support for assisted dying was based on a liberal interpretation of their patients' autonomous wishes. As well as these differing attitudes towards assisted dying, there were other examples where the orientations diverged, such as their approach to the healthcare encounter in general and the importance of ethical reflection, as I have indicated in the previous section. In this section, I will explore the influences that may have led to these differences.

If it is accepted that people's values are formed under the influence of the social experiences and structures that they encounter during life, it is reasonable to question whether the experiences of the members of the two specialties were different, and if so whether these differences were relevant. As all the participants were UK or Irish citizens and trained in those countries and all were practising in the North of England, it might be expected that they would be influenced by the prevailing political and social values of the society that they grew up in, and now live in. It has been said that the liberal welfare state exists as a compromise between, on the one hand, liberty, as exemplified by the free market and public expectations about peoples' rights, and on the other, equality (Kymlicka, 2002; Rawls, 2005; Wolterstorff, 2012; Forrester, 2019). The equality just mentioned is exemplified by the welfare state, and the NHS in particular. As I have indicated in the literature review, this in turn has led to more socially liberal attitudes towards several issues within UK society, including the acceptance of, and indeed demand for assisted dying (NatCen Social Research, 2017). The other potentially relevant change in UK society has been the decline in religious identity and practice over the last fifty years (Park, 2007). A parallel can be drawn between this tension between individual rights and social obligations in society as a whole, and the doctors' attitudes to assisted dying. I observed a balance between respect for the patients' rights and the doctors' own values (as representatives of the NHS), which differed between the two specialties. Patients' rights tended to dominate the respiratory agenda, but communitarian responsibilities were uppermost for the palliative physicians. In the following paragraphs, I will attempt to unpick the possible influences on this process.

I have considered the potentially differing influences from three perspectives. Firstly, by exploring the motives for choosing a career in medicine and linking specific motives (such as a wish to care) to subsequent choice of specialty, it might shed light on the prevailing values of those specialties. Secondly, the doctors' initial medical identities are likely to have been formed during their undergraduate medical school years and during junior doctor posts, and all the participants progressed through a similar system. Thirdly, I shall explore whether the experience within their chosen specialty had any influence on either their attitudes or their underlying values, accepting that socially constructed values are under constant evolution.

9.4.1 Motivations for medicine

I described the two most common motivators for a career in medicine as 'vocational' and 'a leap of faith'. Whilst for the respiratory physicians, the notion of vocation implied helping people or doing 'good' in a somewhat abstract sense, for many of the palliative physicians, it implied forming caring relationships with individual people. Indeed, four of these doctors had taken time out to visit India as volunteers to take on such a role. Finally, vocation was interpreted in the light of the notion of doctors 'fixing it' and this was linked to the principal aim of respiratory medicine, which was to treat and if possible, cure people's diseases. The 'leap of faith' attitude of some of the people who later became respiratory physicians is more difficult to interpret. The individuals were high achievers with no prior knowledge or experience of medicine, who were encouraged to study the subject because they were bright. In acknowledging the range of opportunities that existed in the profession, they showed an openness of mind and subsequently found what they felt suited them. From this point of view, they had less preconceptions about what a career in medicine might hold.

The other obvious difference between the members of the two specialties was that most of the palliative physicians described a relevant Christian faith, either active or in the past. This observation confirms previous findings by Seale (Seale, 2009b; Seale, 2010)

While such observations cannot be inferred to be causal, it is an interesting observation that these characteristics were described by the participants as existing before they had experienced, or committed to, their subsequent specialty.

9.4.2 Pre-specialty

All the participants commented on their student and early medical careers and described how these informed their subsequent choice of specialty. During medical school, they all received education in medical ethics, and it is noteworthy that of those who referred to this, palliative physicians such as Jessica were interested in this aspect of medical education, whilst the respiratory physicians who expressed an opinion on the subject were not (Kimberley, Joseph).

These observations that those destined to become palliative physicians were motivated by caring, held Christian faith, and were interested in ethical discourse before they actually joined the specialty raises the question of whether they actually represented a different 'social type' from other doctors.

9.4.3 The specialty of respiratory medicine

I have already described respiratory medicine's focus on a biomedical approach towards respiratory diseases and their treatment. Similarly, the BTS supports and encourages evidence based medical practice through the production of guidelines and the coordination of national audits based on these guidelines (Woolhouse *et al.*, 2018; British Thoracic Society, 2019; British Thoracic Society, 2020). These are the elements of the 'good' in respiratory healthcare that the BTS, and respiratory medicine as a specialty, expect their members to aspire to. Furthermore, they mirror those of the RCP (Royal College of Physicians, 2019c). From this point of view, therefore, both the BTS and the RCP are taking a normative position, rather than remaining neutral about good medicine.

The approach to assisted dying is, however, different. Although the respiratory curriculum does require a 'knowledge of the principles of medical ethics' (Joint Royal Colleges of Physicians Training Board, 2020b), it does not offer any specific ethical guidance on assisted dying for its members. As I have already indicated, the RCP's Committee on Ethical Issues in Medicine (CEIM) does provide ethical guidance to the council, fellows and members of the college (Royal College of Physicians, 1985). The background and outcome of the 2019 RCP survey on assisted dying has already been summarised, resulting in the RCP's change from opposition to publicly holding a neutral stance on whether the law should now allow assisted dying (Royal College of Physicians, 2019c; Royal College of Physicians, 2019a). In his defence of this change in stance, the president wrote:

> *It is clear that there is a range of views on assisted dying in medicine, just as there is in society. We have been open from the start of this process that adopting a neutral position will mean that we can reflect the differing opinions among our membership.*
>
> *Neutral means that the RCP neither supports nor opposes a change in the law and we won't be focussing on assisted dying in our work. Instead will continue championing high quality palliative care services (Goddard in Royal College of Physicians, 2019a: 2-3).*

Goddard, on behalf of the RCP, was expressing a liberal egalitarian attitude that respected differing views on the issue of assisted dying, rather than proposing an organisational position that he expected his community to follow. In summarising Rawls' support for liberal egalitarianism, Kymlicka wrote that 'our essential interests are harmed by attempts to enforce a particular view of the good life on people, and so the state should remain neutral regarding the good life.'(Kymlicka, 2002: 217). Another interpretation of the adoption of the neutral stance by the RCP is that by doing so, it was distancing itself from the issue altogether. This reflects the attitude held by William (respiratory), who had not considered assisted dying because it was not relevant to his practice and was too difficult to conceptualise. It seems likely that in adopting a neutral attitude, the RCP was attempting to accommodate a variety of contrasting opinions in a non-confrontational fashion but was also sending the message that it is society's business rather than its own.

9.4.4 The specialty of palliative medicine

On the other hand, palliative medicine has made assisted dying very much part of its business, and I will briefly trace the background to this. I have already described how the specialty of palliative medicine arose from the hospice movement, and how this in turn had been inspired by the charismatic leadership of Cicely Saunders, whose values had largely been incorporated into those of the specialty as a whole. The key principles of Saunders' approach were: pain and symptom control based on scientific evidence, developing a close relationship with the patient, holistic care (attention to physical, psychological, social and spiritual concerns), the importance of multi-professional care to achieve this, opposition to assisted dying and that it was underpinned by Christianity. Although all these principles were incorporated into the palliative medicine philosophy, the dilution of Christianity in the current UK secular and multi-faith society has been recognised by the use of the term ’spirituality’ rather than Christian faith. The process of the assimilation of her values into the philosophy and practice of UK palliative medicine has been interpreted as being achieved through the process of routinisation, as I have described (Weber, 1969; Weber, 1978; James and Field, 1992; Seymour *et al.*, 2005). According to Weber, after routinisation, the relevant community develops democratic processes and rules that maintain the principles that were expressed by their charismatic leader in the first place. Weber described such a rational society in the following terms: ‘resting on a belief in the legality of enacted rules and the right of those elevated to rulership under such rules to issue commands’ (Weber, 1978: 215). Three events, Saunders’ retirement from clinical activity, the recognition of palliative medicine as a specialty and the formation of the APM in the late 1980s, could be seen as stages within a Weberian process of a progression from charismatic leadership to routinisation (Overy and Tansey, 2013; Doyle, 2015; Clark, 2016). If Weber’s theory is accepted, then the routinisation of palliative medicine legitimised its leaders to issue commands, such as to reject assisted dying, and this is one interpretation of the specialty’s polarised attitude towards the issue.

Another way of interpreting the development of palliative medicine and its values is to consider it in terms of being a communitarian movement. In chapter 2, I explored the possible relevance of communitarianism to this study, both at an individual level (autonomy and social responsibilities between people) and at a political philosophical level (social structure of society). I have already described a relationship between Christian values and communitarianism. For communitarians, at a personal level the focus for an individual would be on being a member of that community, respecting its traditions and having both responsibilities for, and expectations of her fellow members. Communitarians would thus want to protect and nurture the vulnerable within their own society (Selznick, 1987; Bell, 2016; Eberl, 2018). Secondly, in the Communitarian society, ‘the good’ is defined by the long-standing traditions that exist within it, and which the state expects its members to adhere to (Kymlicka, 2002).

When Saunders was developing the St Christopher’s Hospice project, she had been concerned with two organisational issues, the religious affiliation and whether it should be a religious or medical community (du Boulay and Rankin, 2007; Clark, 2016). Eventually it was decided that it would be ‘a religious foundation based on the full Christian faith in God’ (Clark, 2016: 93). In doing this, she defined the ‘good’ in terms of faith, but she also defined the ‘good’ in relation to care of the dying. Saunders’ attitudes towards the management of people approaching the end of life, and her rejection of assisted dying, can be interpreted in Christian terms (the importance of living life until its natural end describes the sanctity of life). It can also be interpreted as an example of the communitarian attitude that it is important to support and nurture the vulnerable in society (Clark, 1998; Clark, 1999; Saunders, 2006). The majority of the palliative medicine participants expressed both Christian and communitarian views about these issues and it was sometimes difficult to separate them. It is also apparent that similar views are to be found in the palliative literature and teaching, although not in overtly religious terminology (Doyle *et al.*, 1993; Doyle *et al.*, 1998; Jeffrey, 2006; Hanks, 2010).

The web-based material and position statements on assisted dying that appear on the APM website send out a clear message that the organisation does not support legalisation which allows assisted dying (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019a; Association for Palliative Medicine, 2019b). In his analysis of communitarian societies, Kymlicka described how such communities define their own concept of the ‘good’ and expect their members to conform to those views (Kymlicka, 2002). It is therefore possible to interpret the APM’s actions as being an illustration of a communitarian society defining the good for its members. The recent correspondence between dissenting members of the palliative medicine community and its executive members would appear to illustrate a communitarian society in conflict with some of its members (British Medical Journal, 2019; Davies, 2019; Lawrie *et al.*, 2019; Scheffer, 2019; Wilson, 2019). In the initial correspondence, five anonymous palliative medicine consultants had described how they felt that the senior members of the APM were stifling free discussion about assisted dying, and that they feared for their careers if they made their feelings of support public. Following a defensive reply from that organisation, a few other responses supporting open discussion followed. These responses resonate strongly with data from my interviews. Several the participants, such as Jennifer, Michelle, and Angela, even though they held the same opinion (that assisted dying is wrong) as the ‘official’ view, believed that the tone and content of the APM’s output was counterproductive and likely to further distance palliative medicine’s views from those of society in general. For instance, Jennifer, who was strongly opposed to assisted dying herself said: ‘By and large, if we communicate well as palliative care clinicians, we can do it better than there being blanket statements above our heads saying, "This is what we believe." I think it's better just to meet someone and then we can sort through what's possible, VERY nuanced all of this and I find the black and white really unhelpful.’ This could be interpreted as illustrating her own autonomous values creeping through the communitarian messages of the APM.

9.5 Conclusions

In this section, I attempt to draw together my findings and produce a conceptualisation of what they mean to me. I have already alluded to the concept of *orientations*, and these can be viewed at individual and organisational levels. As I will show, for each subject area, or domain (for example, the concept of ‘good medicine’), there is a *spectrum* of possible orientations and by and large, the orientations of respiratory and palliative medicine sit at different points on each *spectrum*. In addition, there are some *absolutes*, which are common to both specialties. The domains that I have identified are ‘good medicine’, ‘attitudes towards end-of-life management’, ‘individual philosophical orientation’ and ‘organisational orientation’. I will consider each of these in turn.

9.5.1 Good medicine

The perception of what constitutes good medical practice broadly sits on a *spectrum* ranging from the natural scientific approach, biomedicine through to holistic medicine. These approaches were described in some detail in chapter 2. I have proposed that respiratory medicine’s *orientation* sits firmly towards the biomedical end of the *spectrum*. Palliative medicine is strongly *oriented* towards holistic care, although in terms of the management of symptoms, they would aim towards a biomedical approach. All the participants aspired to a concept of care that was patient oriented, and this is therefore an *absolute* value. For the respiratory physicians, this was interpreted in terms of respecting their autonomy, whilst for the palliative physicians this was mixed with beneficent intentions based on their own values.

9.5.2 Attitudes towards end of life

For the purposes of this discussion, I am imagining the scenario of a patient approaching the end of life, who is suffering and requesting it to be shortened. The *spectrum* might range from providing all possible medical interventions to sustain life, to stopping life prolonging treatments, to the generous use of symptomatic treatments to 'ease the passing' (for example as consistent with the doctrine of double effect (DDE)), and finally to assisted dying. The palliative *orientation* would be clearly towards the withdrawal of life sustaining treatments if they were perceived to be unacceptable but would stop short of DDE or assisted dying. The respiratory *orientation* would be further along the spectrum, but always acting within the law. In this scenario, the *absolutes* for both specialties would be the provision of appropriate symptom palliation and obedience to the law of the land. Another (almost) *absolute* position was that doctors should not kill their patients intentionally.

9.5.3 Individual orientation

For this domain, the *spectrum* is not truly linear, as will become apparent. At one end is the sanctity of life, and parallel with it would be the communitarian view of the importance of valuing and nurturing the vulnerable in society, rather than killing them. During the interviews, it became apparent that most palliative physicians expressed one or both as their preferred *orientation*, but one did not depend on the other. At the other end of the *spectrum*, a liberal respect for the patient's autonomous expressed wishes would dominate. The *orientation* of the respiratory physicians was more widely scattered along the *spectrum* but tending to cluster towards liberal autonomy.

9.5.4 Organisational orientation

To grossly simplify what is very complex issue, the *spectrum* that I propose ranges from communitarianism at one end ('politics of the common good') through liberal equality, to libertarianism at the other ('politics of neutrality') (Kymlicka, 2002: 220). The other proviso is that I consider the RCP to be the proxy for respiratory medicine with regards to the assisted dying debate, as the BTS did not offer any opinion or guidance on the issue. For this domain there appeared to be two separate issues, namely good medical practice and assisted dying.

All three organisations (RCP, BTS and APM) offered firm opinions and advice about their perceptions of ‘good medicine’ in their subject area. These mirrored those described above by the individuals, namely biomedicine and EBM for the BTS and RCP and holistic medicine for the APM. So, from this point of view, all the organisations were *oriented* towards a communitarian approach of defining the ‘good’. The difference between the RCP and the APM became evident in the RCP assisted dying poll, in which the APM maintained its communitarian attitude and told its members how it expected them to vote in the poll. On the other hand, the RCP encouraged its fellows and members to vote ‘in accordance with their own conscience’ (Royal College of Physicians, 2019f). Its proposal to adopt a neutral stance towards assisted dying, following the poll was further evidence of its liberal attitude towards the issue. However, it is not clear what a ‘neutral stance’ really means or was intended to mean. It can be interpreted that the RCP considers assisted dying as a societal issue, rather than a medical one. This would be supported by the evidence in this thesis, which was that most respiratory physicians supported people’s right to self-determination at some level, although they themselves would not necessarily choose it for themselves or be willing to be directly involved in the process. Unless the government changes its own stance, this change in official position by the RCP does not change anything.

9.6 Final Thoughts

There have been several attempts to conceptualise the relationship between doctors, patients, and illness, since Parsons’ 1951 publication (Parsons, 1951; Freidson, 1970; Johnson, 1972; Jewson, 2009). In his proposal of cosmologies, Jewson provides an historical interpretation of the development of medical knowledge, and he linked it with the sponsorship of medicine: ‘The Mode of Production of Medical Knowledge’ (Jewson, 2009:623). This approach provided an interpretation of the ’state of play’ of medicine over three periods of time, and several additional cosmologies, such as the influence of pharmaceutical industry and public health have been proposed since the original paper in 1976 (Armstrong, 2009; Nettleton, 2009; Nicolson, 2009; Prior, 2009). However, they do not provide an interpretation of the differences in approach towards medical knowledge and practice that exist today between different individuals or disciplines within the UK medical profession. My proposed framework of medical *orientations, spectra and absolutes* aims to address this. For each *orientation,* there is a *spectrum* of potential behaviour, with the extremes joined by compromise positions. As a clinician myself, I am aware that medical decision-making is characterised by compromises between alternatives, benefits with side effects, and this model suits such behaviour. Despite these variations, there are also some *absolutes,* which are common to all practitioners. These include the importance of obeying the law, and of putting the patient at the centre of the medical interaction. Another difference between this model and Jewson’s is that medical ethics does not figure in the cosmologies, despite its importance in current day medical practice.

In the final chapter, I will reflect on the relevance of the study and its conclusions. In doing so, I will explore the strengths and weaknesses of the methodology and my own part in the whole process. Finally, I shall speculate on how my findings could be taken forward in the future.

Chapter 10. Summary and Critical Reflections

In this final chapter I shall summarise the key and new findings that have arisen from this piece of research, as well as the concepts that I have developed from these findings. I shall outline how I think this adds to the current literature on the subject. Following this I will give a brief reflection on the research process, focussing on the design of the research and a reflexive view on my own influence on the design and conduct of the interviews and, more importantly, the interpretation of the data. Finally, I will speculate on how the findings might contribute to future work.

10.1 New Knowledge

My main interest in this research was to explore attitudes and values of the members of two groups of physicians, who are those specialising in respiratory and palliative medicine. The exploration focussed on issues such as how they viewed good medical care in general, as well as attitudes towards ethically sensitive issues at the end of life, including assisted dying. I have compared these individual views with those of each specialty, as are identified in their specialty training programmes, by their specialist societies and by the Royal College of Physicians. From these data, I have developed the concept of *orientations* in attitude towards the issues just outlined, bearing in mind that each *orientation* lies on a *spectrum*. I have also shown that the individuals' orientations tended to match those of their specialty. Finally, I have proposed a structure whereby the professional organisations seek to engage with their membership about the issues that I have described. I shall summarise the key (and new) conclusions in three sections, actual findings, relationship with specialties and new concepts.

10.1.1 Conclusions on the substantive topic

I engaged in this research because of my curiosity about apparent differences in the values of the members of the two specialties and I wanted to understand how deep they went. I have confirmed that there were several key differences as well as several interesting similarities between the attitudes of members of the two specialties, and I have described these in the preceding chapter. Through my analysis of the data, I have developed an innovative analytical framework which I have used to interrogate the data in clearer detail.

The similarities between the specialties, which I have called *absolutes*, relate to their role as doctors in the UK. Both are medical specialties within the governance of the General Medical Council and the Royal College of Physicians. These similarities included putting the patient at the focal point of the medical interaction, in other words they valued patient centred medicine (Balint, 1969; Mead and Bower, 2000). Another common view held by the participants was a strong reluctance to be involved in the assisted dying process, if it were to be made legal. The view that doctors should not intentionally kill their patients was held by all the participants. This links to the third commonality, which was their respect for obeying the law of the land.

The differences that I exposed during the interviews existed in two broad domains, good medical care, and end of life ethical dilemmas, which included assisted dying, even though it is currently illegal in the UK. The respiratory physicians broadly viewed medical practice through a biomedical lens. This was characterised by valuing a scientific approach to the study of disease processes and their treatment, coupled with the application of evidence-based medicine (Prasad, 2013; Greenhalgh, 2014; Sheridan, 2016). In contrast, the palliative physicians' approach was to seek to understand their patients' actual suffering, and by forming a caring relationship with the patient, help them to live through it. Their therapeutic approach was to explore the physical, emotional, social, and spiritual components, and in adopting this holistic approach provide appropriate palliation. Another element of medical care that exposed different *orientations* between the specialties was in relation to ethical theory, reflection, and discourse as a guide to good practice. It was evident that the palliative doctors valued the contemplation of such issues as part of their daily practice, whilst the respiratory physicians did not, but drew on their experience and wisdom of their seniors when they were trainees.

Of real significance were the differences between the participants' attitudes towards assisted dying, which I had intuited, but did not understand. The great majority of the palliative physicians were strongly opposed to it, based on the sanctity of life, and the need to protect and nurture the vulnerable in society (a communitarian *orientation*). On the other hand, although their support was not as strong as the palliative physicians' opposition, the respiratory physicians generally supported the notion of patient choice at the end of life. I conceptualised a *spectrum* between absolute opposition and absolute support for assisted dying. The palliative *orientation* was strongly towards one end, whilst respiratory was positioned nearer the middle, but towards the other end.

The RCP poll on assisted dying revealed a clear difference in opinion on the issue, between palliative medicine and the other medical specialties and this was confirmed during the interviews. However, the poll was unable to offer any insight into why this should be. This degree of understanding of the differences in attitudes towards assisted dying has only been achieved through the qualitative approach that I used for this study. Such a comparative study has not been undertaken before, and although palliative medicine's opposition to assisted dying is well documented (Saunders, 2006; Seale, 2009b; Seale, 2009a; Seale, 2010), it has not been interpreted at an individual level amongst palliative physicians, and never compared with another medical specialty. This understanding has been achieved through the analytical framework that I have developed during this research.

10.1.2 Implications for the specialties

Through a review of the origins and development of the two specialties, I have proposed a plausible account of the emergence of these distinct *orientations*. I have proposed that the RCP and BTS express the same *orientations* towards biomedicine and evidence-based medicine as the respiratory participants in this study. Similarly, the APM website and palliative specialty training indicate an *orientation* towards care and holistic medicine, although they acknowledge the importance of a scientific approach towards symptom control. In chapter 3, I was able to show that such an *orientation* was evident in the work and writings of Cicely Saunders (Saunders, 2006).

The relationship between participants' values and those of their respective organisations regarding assisted dying is a little more difficult to unravel. There appears to be a clear alignment between Cicely Saunders views on the topic, those of the APM and the attitudes expressed by the palliative participants in their interviews. However, a number of these doctors did not appreciate the way that the APM passed on the message, despite agreeing with the basic message, which was opposition to assisted dying. I have interpreted this attitude as being underpinned by a communitarian *orientation*, both towards protecting vulnerable patients as members of society and at an organisational level, by defining the nature of the ‘good’ and expecting its members to concur. It was evident that palliative medicine was an outlier in the RCP assisted dying poll (Royal College of Physicians, 2019a), and this raises the question of whether opposition to assisted dying is a central part if the specialty’s identity. I have already described the prominence of the subject on the APM website (Association for Palliative Medicine, 2017; Association for Palliative Medicine, 2019a).

The respiratory physicians predominantly displayed a liberal approach towards their patients’ autonomous wishes in the context of the assisted dying debate, and this *orientation* was reflected by the RCP in their handling of the poll on the issue (Royal College of Physicians, 2019b; Royal College of Physicians, 2019a). In proposing to adopt a neutral position, and allow their fellows and members to vote with their conscience, The RCP was demonstrating itself to be a liberal society in relation to assisted dying (Kymlicka, 2002).

If a specialty in the medical profession were to recognise the orientations that it valued and led to good practice, it could endeavour to nurture them through its training programmes.

10.1.3 New concepts.

In this study, I have explored the *orientations* of two specialties through the testimonies of their doctors and have provided an insight that could not have been achieved through a quantitative methodology. My analytical framework, based on the concepts of orientations, spectra and absolutes brings a new and nuanced insight into the critical discourse on medicine. It provides a framework whereby the philosophy of medical care can be interpreted, and comparisons between different approaches can be made. Jewson linked the understanding of illness and the medical approach to it, with the sponsorship of medical practice overall (Jewson, 2009). He described these cosmologies over three periods of time. Although they offered explanations for the overall medical approach to illness during these times, they did not give any insight into how the individual doctors at each time viewed their own role, nor did they give any consideration to potential differences between different types of doctor. This study offers a framework which could be used to compare and contrast different groups of doctors, or even members of other professions in which the formation of values is necessary for the conduct of the occupation.

10.2 Personal Reflections

There were two areas in this research process, where I was aware that my own personal history and professional experience could have an influence on the conduct and outcome of the research. The first relates to the interview process and the second to the interpretation of the data and subsequent conceptualisation. I have already indicated that I was initially trained as a respiratory physician, and I practised as such for more than 10 years. During the process, I had been exposed to similar influences that the respiratory physicians described in their interviews. I had also experienced similar feelings of respect for some of my senior colleagues, as Robert did when he said: ‘I was just completely inspired by the people I worked with. I thought the consultants on the respiratory ward were magnificent and (gave an) exceptional standard of care. ’ With this background, I have asked myself why I made the move towards and into palliative medicine. The reason was my own dissatisfaction with the care that I could personally offer, and the lack of a palliative medicine service in the hospital that I worked in. I undertook specialist palliative care training on sabbatical leave from my consultant post and obtained specialist registration in 1996. In the later years of my career, I spent progressively more time in palliative medicine and less in respiratory. The point of this lengthy introduction to my personal reflection is to point out something that I had not fully appreciated before engaging in this research. I have realised that I am more fully grounded in the culture of respiratory medicine than I am in palliative medicine, and I can speculate that this is largely a property of the training programme that I underwent and the professional relationships that I developed at that stage of my career. Such an apparent bias needs to be considered, and I will attempt to do so later.

In terms of the actual interview process, the most positive aspect of having worked in both specialties was that I had ‘shared the experience of the research subjects’ (Berger, 2015). In other words, I could understand the issues that the participants were describing, without the need for clarification and this helped with the spontaneity of the interview. Likewise, having been involved with both specialties, I found it easier to prepare the topic guide, and was able to capture useful data from the first interview without the need for practice interviews. The other area of the interview process that could have been problematic was when addressing issues where the values of respiratory and palliative physicians differed, such as attitudes to assisted dying. As I have mentioned, one of the main reasons for doing the study was my surprise at the strength of palliative medicine's opposition to it. This surprise clearly positioned me as being aligned with the respiratory point of view. In fact, for reasons that I mentioned in chapter 5 (experience in difficult interviews and a training in person-centred therapy), I believe that my own position did not interfere with the interview process.

The other relevant area, potentially of more concern, was in my interpretation of the data within the transcribed interviews. Would my own position on an issue bias how I interpreted someone expressing an alternative view? An example that arose related to the palliative physicians' apparent preference for moral reflection and deliberation in contrast to the lack of interest shown by the respiratory physicians. In chapter 7, I quoted the example of Jessica, a palliative physician and Christina, a respiratory physician, describing similar events (the withdrawal of assisted ventilation at a patient's request). It was apparent that whilst Jessica felt that the experience merited ethical reflection afterwards, Christina took it in her stride as a part of her clinical duty. A reasonable question was posed to me as to whether I thought Christina was ethically naïve, or Jessica was over-sensitive (not surprisingly, my own position would probably be somewhere in between). In response, I would say that these tendencies are a part of each specialty's *orientation*, without judgement. As I indicated, both Jessica and Christina's actual care, as described by them, appeared to be equally professional and ethically appropriate, so I did not want to conclude that one did a 'better job' than the other. Having given this example however, I am aware that my own *orientations* are generally more aligned with those of the respiratory physicians, but I believe that my acknowledgement of my own inbuilt *orientations* has not biased the analysis and interpretation of my data.

10.3 Future Directions

In chapter 2, I reviewed the existing sociological literature on the factors that have been thought to influence the practice of Western medicine overall (Jewson, 2009; Nettleton, 2013; Scambler, 2018). In this research, I have focussed the analysis down to both individual and specialty levels and I have described a new analytical framework to explore the relevant influences on the conduct of medicine in its broadest sense. It is apparent that there is a complex interplay between these factors, which results in visible differences in the doctors' approach at specialty level. For instance, I have shown that biomedicine and liberal autonomy are important to respiratory medicine, whilst holistic care, faith and communitarianism are key values in palliative medicine. The notion of *orientations* offers a more nuanced way of exploring the more subtle differences between different groups of doctors, and how these differences arose in the first place. This, therefore, adds another potential layer to the sociological study of medicine, giving a greater insight into the profession of medicine as well as its component parts. The framework could also be applied to other professional or occupational groups in which conflict or change was the subject of consideration.

I have shown that orientations are the processes that fix people in their views, so this framework could be applied more widely within healthcare policy, to help the understanding of differing views, particularly when change is proposed. The issue of assisted dying is one example that springs to mind. I have described how, in the case of Nicklinson [54], the judges made it clear that legitimisation of assisted dying should be decided by parliament, rather than through the courts. An understanding of the orientations of the interested parties, and how they developed would be useful to help the politicians come to their decision in a parliamentary debate on the subject. This begs the question of whether parliamentary debate would be able to change the opinion of the MPs, whose own orientations would presumably have already been formed by their earlier experiences and influences. The question arises as to whether individuals' orientations are fixed or, like 'floating voters' in the General Election, priorities may change.

Another potential application of the notion of orientations would be in mediation at an individual or organisational level. It would enable each party to understand the important drivers that influence decision-making in a non-confrontational way.

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[54] R (Nicklinson) v Ministry of Justice; R (AM) v Director of Public Prosecutions [2014] UKSC 38.

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