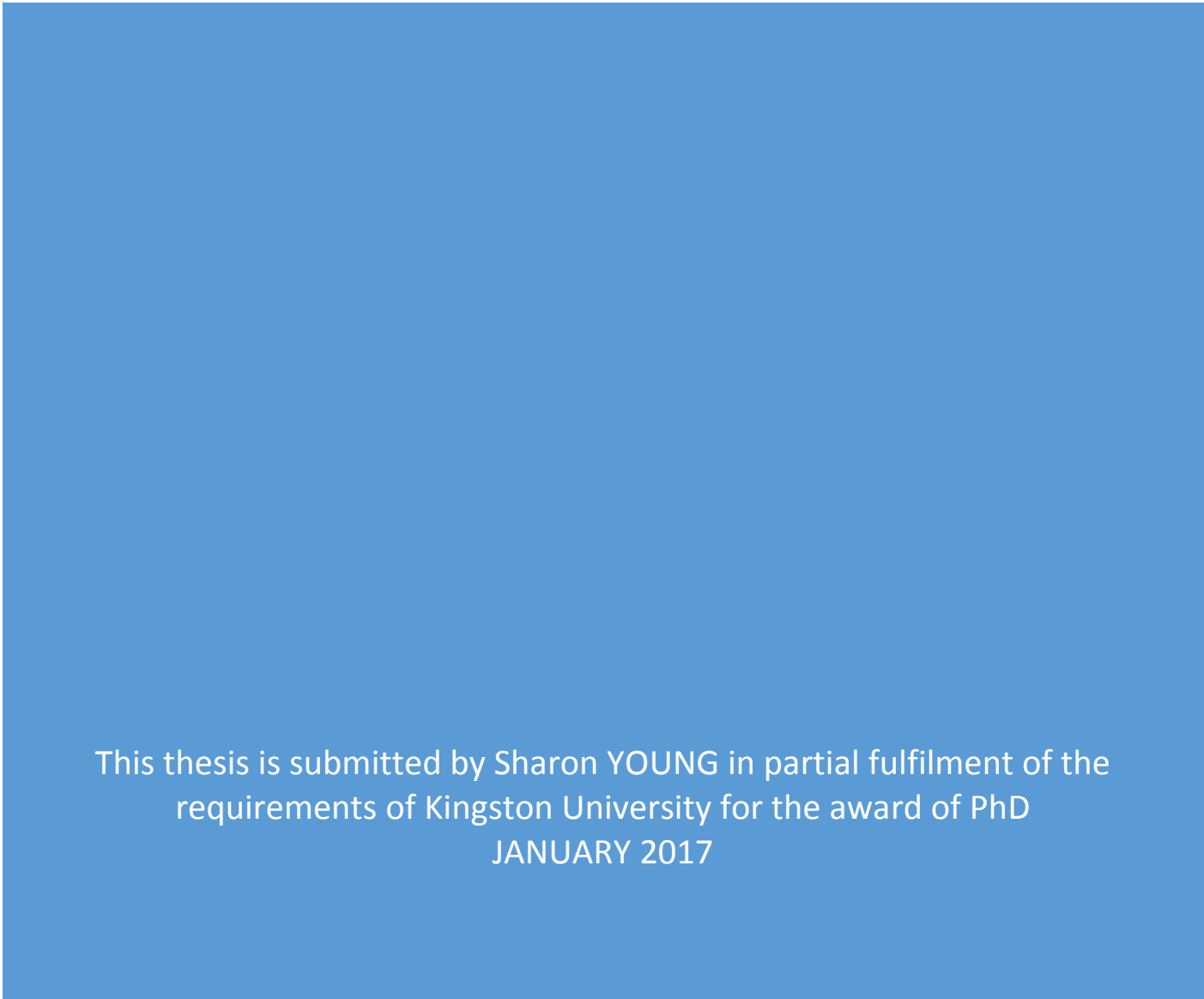




A RIGHT TO DIE? EXAMINING THE CENTRALITY OF
HUMAN RIGHTS DISCOURSES TO END OF LIFE
POLICY AND DEBATE IN THE UK



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ABSTRACT

Death and dying are emerging as substantial topics for political and social debate in contemporary UK society. The management of end of life, traditionally defined within a medical model of care, is being challenged by a cultural shift that is apparent in the changing trajectory of dying, increasing healthcare consumerism and a rising human rights rhetoric. To a significant extent, liberty to determine one's own death, and to request assistance to die, has come to be articulated by some as a "right to die". Human rights discourses grounded in the values of dignity and freedom of choice are important and relevant to dying in the UK. These discourses have the potential to influence law and policy, practices and public opinion on end of life. However, there is no sociological analysis of *how* or *when* rights have come to be appropriated in an end of life context and no explanation of *in what way*, or to *what extent*, social actors are using rights discourses in relation to death and dying.

This research explores the centrality of human rights discourses to end of life policy and debate on assisted death in the UK. A broad social constructionist approach to rights is taken to illuminate the ways in which selected actors understand and articulate rights in an end of life context, and how, as a result of this, a right to die may be conceived. It includes the examination of: current UK law and policy documents; transcripts of the historical and contemporary House of Lords debates; a case study of a highly influential organisation (Dignity in Dying) who campaign to legalise assisted dying, and three focus group discussions with Death Café Hampstead participants. Analysis of the data reveals that rights discourses involving individual liberty, dignity and human vulnerability *are* central to defining the end of life debate and policy. A notion of *rights at the end of life* has impacted our perception of dying but in ways that are complex, and arise as a reflection of dying at a specific period in time.

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CONTENTS

1. Introduction	6-17
1.1 Background context	6
1.2 Research focus	11
1.3 Outline structure of thesis	14
2. Literature Review	18-40
2.1 Challenging medicalised death	18
2.2 Determining the good death	24
2.3 Constructing assisted death	32
3. Human rights framework	41-62
3.1 Foundational approaches	42
3.2 Anti-foundational approaches	50
3.2.1 Legal positivism	51
3.2.2 Social constructionism	54
3.3 Alternative approaches	59
4. Research Methodology	63-82
4.1 Conducting the research	63
4.2 Research design	64
4.3 Ethical considerations	79
5. Law and Policy	83-111
5.1 UK Law	84
5.2 Case examples	90
5.3 Global perspectives	101
5.4 End of life policy	105
6. Historical and contemporary debates in the House of Lords	112-139
6.1 Voluntary Euthanasia (Legalisation) Bill 1936	114
6.2 Patient (Assisted Dying) Bill 2003	118
6.3 Assisted Dying Bill 2014	127

7. Case study on Dignity in Dying	140-165
7.1 Foundations of the organisation	141
7.2 Aims and objectives	143
7.3 Campaign for Dignity in Dying 2014	144
7.4 Voices within Dignity in Dying	152
8. Focus group discussions with Death Café participants	166-190
8.1 Understanding rights	167
8.1.1 Dignity	170
8.1.2 Suffering	175
8.1.3 Individual liberty	178
8.1.4 Capacity	181
8.2 Alternative perspectives on death and dying	184
9. Conclusion	191-206
9.1 Contextualising rights at the end of life	192
9.2 Contemplating human rights	193
9.3 Advancing human rights principles to challenge UK law and policy	197
9.4 Articulating rights explicitly and implicitly to debate assisted death	199
9.5 Campaigning at the end of life through rights-framed approaches	201
9.6 Using rights discourses to contemplate death and dying	204
<i>Appendices</i>	207
<i>Bibliography</i>	219

LIST OF FIGURES, TABLES, AND ILLUSTRATIONS

Figure 3.1 Contrasting rights-based and rights-framed approaches in development campaigning	58
Figure 4.4 Focus group demographics	77
Figure 5.1 Oregon DWDA Prescription Recipients and Deaths 1998-2013	103
Figure 6.1 Overview of the 1936, 2003, and 2014 House of Lords Bills and debates	113
Figure 6.2 Comparing the discourses and arguments of the 1936, 2003 and 2014 House of Lords debates	137
Figure 7.1 2014 Dignity in Dying campaign newsletter, issue 3 of 3	146
Figure 7.2 2014 Dignity in Dying “cartoon”, campaign newsletter, issue 3 of 3, p5	148
Figure 7.3 “Home” page Dignity in Dying website, June 2014	149
Figure 7.4 Tag cloud to show word frequency in Dignity in Dying personal stories	155
Figure 7.5 Illustrating Dignity in Dying’s use of a rights-framed approach	164
Figure 9.1 Illustrating how, when, for what purposes, and to what extent rights discourses feature in the data	197

CHAPTER 1

Introduction

Each year approximately 460,000 people die in England (Gomez et al, 2010). Contemporary dying across the UK has become a somewhat standardised and sanitised experience, largely overseen by the medical profession, within a clinical environment. Significant advances in clinical research and the development of medical technologies have enabled earlier diagnosis and an ability to prolong the lives of seriously ill patients including those suffering from progressive or terminal illness. Successful treatment of previously fatal infections, combined with a reduction in sudden deaths, has resulted in a longer life expectancy and a growing elderly population to the extent that the percentage of deaths occurring in the group of people aged 85 years or more is predicted to rise to 44% by 2030 (NHS England, 2014). Against this ever expanding technical-medical model of healthcare, Parkes et al (1997:4) highlight that “[d]espite all the advances in modern science 100% of people still die”. Death is an *inevitable* phenomenon, which will be *universally* experienced and, on this basis, *how* people die is an issue of broad social relevance.

1.1 Background context

Dying in late modernity in the UK typically involves a progressively ageing population diagnosed with a chronic medical condition. This is frequently characterised by multiple ailments and periods of sporadic deterioration, facilitating longer time to reflect upon impending death and the choices to be made. The notion of *choice* that traditionally determined decision-making in everyday life is evolving to encompass decision-making over *where*, *when* and *how* we die and this is being more openly discussed in the public domain. As one example, Dying Matters was established in 2009 to support the implementation of the Department of Health End of Life Care Strategy 2008. This is now a coalition of over 30,000 members including NHS organisations, voluntary and independent healthcare sectors, and community initiatives across England and Wales. Their mission is to help people talk more openly about dying, death and bereavement, and to make plans for the end of life that enable people to attain “a good death”¹ (Dying Matters, 2015). Dying Matters is encouraging people

¹ A good death was referred to as early as the 17th century originating from the Greek word “euthanasia”. It traditionally defined a gentle and easy death, “Eu” derived from the Greek meaning well

to communicate their preferences for the end of their lives – what they want to happen when they are approaching death; what they want when they are dying, and what they want to happen afterwards (Dying Matters, 2015).

There are also a number of social initiatives and national events including London Month of the Dead, Kicking the Bucket Festival in Oxford and a growing Death Café movement², all of which suggest an increasing visibility and discussion around end of life issues. As part of this research, I myself acted as a regular facilitator at monthly Death Café events in Hampstead, London over a two year period. The individuals I encountered were comfortable speaking about death and dying. Death Café participants shared their experiences of serious illness or bereavement and thoughts about end of life. This included articulating their own perceptions of a good death that mostly involved aspects of choice, as the following excerpts demonstrate:

I think most people do, given the choice, want to die in their own homes...What would be nice is to go quietly in your sleep when your body says it's had enough, just drift away that would be the nicest way, not a violent death. If you know that the end is near you could put your affairs in order so your mind is at peace as well as your body and you just drift away (Male, aged 65)³.

I would really like to be helped to go on my way without a slow or a drawn out death, if I request that, and to be able to die at home, not in hospital, or in the outdoors somewhere. In the garden would be nice. I don't want to be kept alive in a hospital on a machine surrounded by people I don't know (Female, aged 50).

Freedom of choice that embodies individualism, self-determination⁴ and successful management of the self has become an especially important concept in healthcare and is

and “thanatos” meaning death (*Collins English Dictionary*, 2012). This historic reference to euthanasia that constituted a good death contrasts with the contemporary understanding of euthanasia which incurs criminal liability.

² Death Cafe was originally conceptualised by a Swiss sociologist and anthropologist, Bernard Crettaz, under the name Café Mortel and then developed in the UK, in 2011, by Jon Underwood in London. It operates as a not for profit social franchise with the objective “to increase awareness of death with a view to helping people make the most of their (finite) lives” (Death Café, 2014). Groups of people, often strangers, meet to enjoy refreshments and discuss death with no agenda, objectives or themes. They do, however agree to rules of respect and confidentiality.

³ Participants’ contributions have been anonymised in the same manner used for focus group discussions in this research. Further details are given in section 4.2.

⁴ In a conventional human rights context, “self-determination” typically refers to minority or group rights in relation to social, political economic determination. However within end of life debates and literatures, the concept of “self-determination” is more commonly articulated in relation to the context of personal autonomy, involving a right to decide one’s own end. The latter approach (“self-determination” as personal autonomy) will be used throughout the remainder of this thesis.

argued by some to be dominating the discourse on end of life (Judd and Seale, 2011:225). In contemporary UK⁵ society, the notion of *choice*, where individuals determine the manner and timing of their own death, demonstrates a cultural shift in thinking for reasons that are not immediately obvious and warrant closer inspection. In February 2015, the *Choice in End of Life Care* report was published by the Department of Health. This review, based on wide public engagement, highlighted many negative incidences where individuals had not experienced having control over their death or had not received, in their opinion, high quality care. In doing so, the report championed greater choice in end of life care. It advised actions for Government, wider society and the healthcare system regarding how this could be achieved. Particularly interesting was how this well-intentioned, but vaguely defined, proposal in this document was supported by, what was articulated as, a “*right* in the NHS Constitution for everyone to be offered choice in end of life care and have these choices and preferences recorded and held in their individual plan of care” (*Choice in End of Life Care*, 2015). The report also revealed a previously uncharted demand for end of life care to reflect personal values and preferences that enhanced personal *dignity* (*Choice in End of Life Care*, 2015). Dignified care and dignity-conserving practices feature prominently in healthcare policy and NHS strategies. Provision for end of life care is underpinned by concepts of *liberty* and *dignity* that are frequently expressed in connection with *rights*, but there is no analysis of why these strategies are being grounded in, or articulated as, rights.

Recent indicators of interest in the end of life debate are evident through proposals in the House of Lords (2014) and the House of Commons ⁶(2015) to change the law and establish a legal *right to die*. From a political perspective, the current debate on assisted death is largely argued in terms of rights. The complexity of the dilemma can be illustrated through the contribution of Baroness Kennedy in the most recent House of Lords debate who described assisted dying as:

...one of the most challenging moral issues of our times. On the one hand, we are dealing with the right to individual autonomy and to bodily integrity and with the right to make decisions about our own lives. So it is a profound issue of human rights. On the other hand, there is a need to preserve the wider fabric of an ethical society with an overriding principle that human life is to be valued and guarded against violation and abuse (House of Lords, 2014 col 872).

⁵ The debate on assisted dying is generally indicative of UK sentiment. Some aspects of law and policy differ between countries and these are clarified in Chapter 5 that addresses law and policy in depth.

⁶ The most recent Assisted Dying Bill in the House of Commons was raised by Labour MP, Rob Marris. It did not pass the second reading debate on 11th September, 2015.

Essentially, the current assisted dying debate rests between two powerful, competing claims. One perspective emphasizes the right to individual liberty in choosing the manner and timing of one's death. Individuals in favour of legalising assisted death commonly argue on the basis of respect for personal autonomy and human dignity; rational individuals are entitled to exert free will based on informed choice to make decisions that affect their bodily integrity in accordance with their own values and beliefs (Warnock and McDonald 2008, Howarth 2007, Battin 1994). Especially during a protracted or painful illness, requests for assistance to die could be associated with, and justified through, a desire to avoid actual or anticipated suffering and die a dignified death. The counter-argument highlights the sanctity and value of all human life and the responsibility that democratic states attach to protecting the rights of vulnerable third parties against a relaxation in the current law. Opponents are concerned that if a right to die was granted, albeit to those meeting the safeguarding criteria, it may potentially lead to abuse as the lives of elderly, ill and disabled individuals become less highly regarded (Jeffrey 2009, Keown 2002).

Mainstream UK media, including national, regional, and local newspapers and the British Broadcasting Corporation (BBC) television news has also demonstrated a growing interest in the end of life debate. Media representation has been generally supportive of appeals for an assisted death, evidenced through their use of graphic, emotive testimonies to highlight the daily lives of those requesting assistance to die as being undignified and unbearable (see, for example *The Telegraph* 2013, BBC News 2012, *Daily Mail* 2012). The personal stories of individuals requesting assistance to die, cases of assisting death and people travelling to the Swiss clinic Dignitas to end their lives have been covered extensively (see, for example BBC televised coverage of Simon Binner 2016, Paul Lamb 2013, Tony Nicklinson 2011, Dr Anne Turner 2006). Typical media discourses, argued in terms of rights, are illustrated in the headlines by Bannerman and Gibb, "Life is cruel, says Paul Lamb taking on right to die campaign" (*The Times*, 20th April, 2013 [online]) and Stanford, "Why must I go on living like this?: Locked in stroke victim Tony Nicklinson has embarked on a landmark legal battle to win the right to die" (*The Daily Telegraph*, 2nd December, 2011:35). In the public domain, the mainstream media and civil society organisations have had a role in contributing to the historical changing and shaping of attitudes toward death and dying. Constructing specific discourses that frame the notion of assisted death as a *right to die* has implications for the terms of the current debate.

A number of what are commonly referred to as “right to die” organisations are campaigning for the legalisation of assisted death. Dignity in Dying (DiD), as one such national organisation, has commissioned opinion polls and surveys that demonstrate very high levels of public support for assisted dying. British Social Attitudes (BSA) surveys from 2007 and 2010 respectively claimed that 80% and 82% of people “probably or definitely agree that a doctor should be allowed to help end the life of a person suffering from a painful, incurable disease at their persistent request” (DiD, 2013). Following the most recent Populus poll, commissioned by DiD in March 2015 with 5,018 British adults, the statistic has remained consistent and this is highlighted on the Dignity in Dying website “82% of adults support a change in the law on assisted dying for terminally ill adults” (DiD, 2016). Interestingly, this poll that claims to be representative of the British public, does corroborate support for a change in law across all categories of people represented in the employment sector, voting intention, readership and tenure (Populus, 2015). These figures suggest that a cultural shift is occurring. The notion of choice at the end of life is elevating personal decision-making to a level that would enable individuals to determine the timing of death and to request assistance from another person to achieve their desire. Polls may be criticised as inadequate to explain in-depth personal motivations and reasoning regarding one’s own death (see Lewis 2001, Noelle-Neumann 1993, Dworkin 1993), but research in the form of polls, surveys or questionnaires can give a general indication of thoughts at the end of life. All recorded statistics to date do support this overwhelming public majority view in favour of physician assisted suicide⁷.

As part of the 2011 campaign initiative for Dignity in Dying to target members of the public, leaflets with the wording “*Your life. Your death. Your choice?*” were delivered to private homes, including my own, in the London area (see Appendix One). This leaflet initiated a personal interest in end of life by provoking consideration of *how*, and to *what extent*, personal choice could, or should, determine the circumstances of one’s own death. I became intrigued to examine the discourses used to define the end of life, particularly in regard to assisted death and to explore how particular discourses, which may be time and context specific, could impact attitudes towards death and dying. Assisted dying is often referred to in the public domain and has been articulated by some social actors as a *right to die*. Sensationalised media focus on high profile “right to die” cases and in-depth coverage of the

⁷Accepting that questions and subjects can be fashioned and manipulated to support particular arguments, a number of different surveys over an extended time period have all shown strong support for assisted dying (see National Opinion Polls conducted between the 1970s and 1990s, European Values Study (EVS) surveys for the period 1981-2008, and British Social Attitudes (BSA) surveys undertaken between 1983 and 2012).

recent political debates on assisted dying suggests that rights discourses have increasing salience. This raises a series of questions about *how* this is happening, *who* is driving this change and *the manner in which* this issue can be thought about. O’Byrne suggests that certain rights or claims expressed as rights only emerge in particular social settings and are based on the culture and context of the community in which they operate (O’Byrne, 2003:39). Calls to legalise a “right to die” are one example of this and this drives the research interest to address the question eloquently posed by Scolding (2011:320), “how can a right to something that inevitably happens to all of us suddenly arise?”

1.2 Research focus

There appears then to be, at present, a high level of public engagement with end of life issues. Changes in the late modern dying trajectory, facilitated by advances in medicine and technology, have raised new areas for debate. Members of the public, as healthcare consumers, are beginning to challenge the established medical model of care by drawing upon discourses that involve concepts of individual liberty and human dignity and a range of social actors are articulating requests for assistance to die as a *right to die*. In a contemporary UK context, claims and entitlements appear to be more frequently expressed in terms of rights as in having a “right to” something. The emergence of new and proposed rights suggests an apparently expanding core of social and moral controversies that are being framed as rights claims in what has been termed by Bobbio (1999) as “the age of rights”. However, there has been little investigation into *how*, *by whom*, or indeed, *when* rights discourses have come to be used and resonate as important in discussions on death and dying.

As new rights are proposed there is an increasing emphasis on personal liberties and less consideration of the wider societal impact so that new rights may be criticised for prioritising individual desires and challenging traditional community values (Etzioni 1997, Glendon 1991, Durkheim 1951). Human beings function as part of a collective society, the ways in which individuals die or are permitted to die, through legal or other provision, will impact the perception of dying by all members of the community. To this effect, communitarian discourses might be applicable to the study of dying. Government legislation on assisted dying raises a dilemma that would involve negotiating the extent to which rights at the end of life are considered individual, fully recognising personal values and preferences, or whether rights ought to reflect expressions of community interest. It is generally argued that while respect for individual rights are important, this does entail a responsibility to consider the wider

implications of individual actions *and* an obligation to reflect upon those choices with regard to the effect upon other members of society (Jeffrey 2009, O' Neil 1996, Finlay 1996, Etzioni 1997, Glendon 1991, Habermas 1990). This is an extant issue for debate among human rights scholars, but one that this research does not engage deeply with. Whilst Communitarian and other rights-based discourses may hold traction in other contexts, this research focuses on analysing the appropriation of rights discourses by the social actors identified as important to the debate and policy in order to understand how rights become embedded in an end of life context.

With such lines of analysis in mind, there are clearly a number of different ways of addressing these questions including philosophical, historical, sociological and normative approaches. Hynes et al (2010:813) suggest that a sociological perspective can help facilitate an understanding of human rights through analysing the context of human rights law, discourses and practices. Their contribution was used to open *Sociology and Human Rights: New Engagements*, a Special Issue of the *International Journal of Human Rights* (published in 2011) where they argued,

Drawing together socially contextualised analyses of the formation and development of human rights law, discourses and practices with sociological understandings of the full social contexts in which they are situated can in our view facilitate critical understandings of the significance of human rights in contemporary societies (Hynes et al, 2010:813).

O' Byrne (2012:830) supports this idea by arguing that sociology is sufficiently equipped with the tools of enquiry that enable a valuable contribution towards a multidisciplinary interpretation of human rights. According to O' Byrne (2012:832), a sociology of human rights might include "the sociological study of the *language* of human rights, an institutional framework within which meanings are negotiated and practices formalised". This perspective can contribute towards explaining: *when*, and to *what extent*, rights discourses⁸ have come to determine the end of life debate and policy; *how* this may have occurred, and; *who* are the key actors shaping the debate. A constructionist approach is invoked in this research because it enables a focus on exploring how different actors understand and articulate rights in particular social settings, and can provide an explanation for how and why rights may emerge and be validated in changing social contexts.

⁸ Acknowledging the wider debate on differentiating between *rights* and *human rights*, both terms are used interchangeably in this thesis and should be understood as the rights one holds on account of being human.

Wilson (2006) highlights the importance of examining how rights operate in social practice and articulates a notion of the “social life of rights” that involves interpreting how different actors understand claims articulated as human rights. His contribution, which will be developed in the following chapter, considers: the role and influence of new social movements; the trajectory of rights claims through political and legal channels, and; how rights claims are formulated by different actors and embedded in different types of social practice (Wilson 2006). Goodale (2007:5) also notes that human rights claims are projected across a wide range of boundaries. Their meanings are subject to interpretation by a diverse range of actors and these meanings are adapted to suit the purposes and practice of everyday life (Goodale, 2007:5). However, as yet, human rights scholars have not given a great deal of attention to interpreting the nature and scope of rights claims in an end of life context.

To explore the controversial assisted dying dilemma as a sociologist, it is necessary to examine the social, historical, political and legal context of death and dying in the UK, first with reference to how rights discourses are being used and understood in the debates on assisted death, and, second, to assess the use of human rights discourses by the actors who have a pivotal role in defining and shaping attitudes on end of life. In order to answer the overarching research question articulated in the title of the thesis, “A right to die? Examining the centrality of human rights discourses to end of life policy and debate in the UK”, the following objectives are specified:

- *examine evidence of rights discourses in UK law and policy;*
- *explore the prevalence of rights discourses in the historical and contemporary debates on assisted dying;*
- *analyse how and why an organisation which campaigns to legalise assisted death use rights discourses;*
- *assess the extent to which public perceptions on death and dying invoke rights discourses.*

Generating and comparing different sorts of texts and evaluating different actors’ perspectives on assisted death, can provide rich data for analysis and enable a comprehensive understanding of the research question (Torrance 2012, Denzin and Lincoln 1998). Accordingly, this sociological approach to a notion of *rights at the end of life* can illuminate how, and for what purposes, a right to assisted death may be conceived, the ways in which rights discourses are used and understood by a range of social actors, and how central or influential this has become. A review of the literatures in the following chapter addresses the work of other

scholars who are interested in end of life research and have driven the research question through illustrating what is already known, and revealing areas where this thesis can contribute to knowledge.

1.3 Outline structure of thesis

There are a further eight chapters in this thesis. Chapter 2 reviews the literature on a Western model of death and dying to set the context for this research. Review of the literature includes clinical studies on assisted death and suggests the management of modern death, primarily defined within a medical framework of care, is being challenged by a cultural change in Western societies that encourages management of the body as a personal project. This shift is reinforced by an emerging emphasis on the contemporary values of liberty and choice in healthcare policy. Individualistic tendencies perpetuate a shift away from a sense of community and more traditional frames of reference leaving individuals to negotiate their own lifestyle choices. Subject to a number of influences and prevailing discourses, the “good death” is emerging as a topic of interest, but review of the literature reveals there is little explanation of how individual liberty, human dignity and vulnerability come to be theorised in this context. This chapter identifies concepts of liberty and dignity understood as human rights discourses as important and relevant to the end of life and to the public perceptions of dying well. However, it reveals an area that has not been fully investigated, namely to what extent and in what manner have different social actors used rights discourses to articulate issues in an end of life context and which positions on rights have they drawn upon to do this?

Chapter 3 explores human rights frameworks to illustrate how rights may be understood and articulated by different actors in an end of life context and how, as a result of this, a right to die may be conceived. Concepts of personal liberty, human dignity and vulnerability of the body are examined and embedded as human rights discourses. This chapter explores foundational and anti-foundational perspectives on rights. A social constructionist conception of human rights grounds and interprets claims to rights within a social context, recognising them as a discursive tool which can be used to influence public opinion and, ultimately, law and/or policy. Social constructionism is explored in relation to (new social movement) organisations that strategically use rights discourses to serve their purposes. This chapter contributes to the research by illuminating perspectives on rights, clarifying positions from which various arguments can be made and suggesting how social actors interpret rights when they express options at the end of life as a “right to die”.

Chapter 4 articulates the research methodology. A broad social constructionist approach is adopted to explore how particular discourses have developed over time and how selected social actors use and understand these discourses. This can give meaning to the ways in which issues of death and dying have come to be received and perceived in society. This chapter clarifies the research objectives then focuses on each of the four stages of the research design: document analysis of current UK law and policy; transcripts of the historical and contemporary House of Lords debates from 1936, 2003 and 2014; a case study analysis of Dignity in Dying, and focus group discussions with Death Café Hampstead participants. For each of these stages, the rationale for selection and process for data collection are discussed, and limitations reflected upon. Through generating and comparing different sorts of data from a range of sources, the research was designed to provide a multi-level analysis of how rights discourses are used at the end of life. This chapter concludes with discussion of the research sensitivities and ethical implications of the study.

Chapter 5 examines UK statutory law and selected government healthcare policy documents that relate to assisted suicide and end of life provision. It highlights areas of ambiguity in the current law in relation to the end of life. These include: the questionable ability to apply discretion in hard cases; confusion over the differentiation between killing/letting die, and the conflict between the Suicide Act 1961 and the Director of Public Prosecution's Policy for Prosecutors 2010. The latter tolerates assisting suicide under particular circumstances. In comparison to the law, human rights discourses grounded primarily in individual liberty and dignity are used prominently, if rather erratically, to define end of life healthcare policy and to outline national standards of care and duties. This chapter includes analysis of the legal appeals of Diane Pretty in 2001 and Tony Nicklinson in 2012 that utilised provision in the Human Rights Act 1998 to petition the higher courts to grant them a right to die. In both the *Pretty* and the *Nicklinson* cases, rights arguments were invoked as the basis for permitting an assisted death and the scope of existing rights deliberated and appropriated in order to challenge current institutional practice. The involvement of the European Court of Human Rights in these cases highlights that the UK exists within a European context. This chapter also provides a brief overview of other countries where assisted dying is legal that could potentially influence the UK debate and policy.

Chapter 6 explores the centrality of human rights discourses through analysis of the transcripts of the House of Lords debates from 1936, 2003 and 2014 in regard to the legalisation of a right to receive assistance to die. The House of Lords has considered Bills on assisted dying on a number of occasions since 1936, and, as part of the UK's political heritage, it has a key role in influencing legislation. This chapter provides an overview of the proposed bills from 1936, 2003, and 2014 and examines the ways in which rights discourses feature in members' arguments throughout the debates to articulate their views and overall positions on end of life. Examining these debates facilitates mapping of specific discourses over time. The 1936 debate was not defined by rights, but compassion. Contributions in the later debates more commonly drew upon rights discourses either explicitly or implicitly to underpin their values and beliefs. Arguments that involved some understanding of rights were evident both in favour of, and opposition to, the legalisation of assisted death and this demonstrates the extent to which the end of life debate is characterised by rights discourses.

Chapter 7 involves a case study on Dignity in Dying (DiD) as the largest national, campaigning organisation supporting a change in law to permit an assisted death under specific criteria. DiD draw upon the values of liberty and dignity to underpin their suggestions that individuals should be permitted "choice", "access", and "control" at the end of life and they claim this is best achieved through their objective to legalise assisted death (DiD, 2016). The organisation strategically uses a rights frame in mediated communication, personal narratives and the voices of Patrons featuring on their website to interpret and position the notion of requested death as being natural and dignified. Analysis of the data collected demonstrates how and to what extent rights discourses, including concepts of autonomy and dignity, have been purposefully utilised. The findings corroborate DiD as an example of an organisation using a rights-framed approach as proposed by Miller (2010) in the context of campaigning on a specific issue.

Chapter 8 analyses data from three focus group discussions conducted with members of the public who attend or are familiar with Death Café, Hampstead. The research explores how an original sample of adults use and understand human rights discourses to contemplate issues at the end of life. Concepts of personal liberty, dignity, suffering and their perception of a "right to die" are discussed by participants to discover how and to what extent rights discourses are used to negotiate end of life priorities and inform their attitudes on death and dying. The data in this chapter suggests initially that rights discourses are not central to focus group participants *all* of whom had difficulty articulating how they understood a right to something.

However, there was widespread and compelling support for individual liberty, with an emphasis on choice and the maintenance of human dignity, as the basis for making claims at the end of life. Choice, as part of an implicit discourse of rights, was frequently highlighted as important to participants who respected this as an expression of free will. Some articulated this as a “right to choose”.

Chapter 9 draws together the data collected from the research. Through a sociological analysis of rights, the use and application of rights discourses was revealed as variable. Understandings of rights were flexible, and there was potential to validate and appropriate rights, including a “right to die” in a new context: at the end of life. The nature of death and dying in late modernity has shifted in a number of ways that reflect the social, cultural and political landscape. The end of life debate and policy in the UK is largely defined through, and operating on, a terrain of rights involving individual liberty, dignity and human vulnerability. A number of social actors draw on rights discourses to support a notion of *rights at the end of life* but in ways that are complex and arise as a reflection of dying at a specific period in history. These findings indicate that further research regarding the reasons *why* rights discourses hold tenure over others in the current social context could build upon this analysis.

CHAPTER 2

Literature Review

The purpose of this chapter is to set the context for the research by way of illuminating areas that have been investigated and identifying those that have not yet been addressed. It is divided into three sections that depict contemporary death and dying in the UK. The first part of this literature review chapter focuses on the established medicalised model of care that has traditionally defined end of life practice and it examines the emerging prioritisation of individual choice and human dignity in healthcare. The second section explores understandings of a “good death” including what this may involve and how this is developed, and influenced by, individual values or beliefs. Concepts of choice and dignity are discussed alongside human suffering that may justify arguments for assisted death. The lack of research into liberty and dignity understood from a human rights perspective, and the implications of what is now apparent as the prevailing discourse of dying, becomes evident here. The third part of this chapter examines dying in a contemporary social context to suggest how a right to die may be constructed. It focuses on the role of human rights discourses and practices, with particular reference to the media and new social movement actors, who use rights discourses to influence how certain issues are received and perceived through their activities and campaigns. There are limited studies on what is commonly termed “right to die” organisations and, as yet, no analysis of their language strategies that invoke rights discourses to conceive a right to assisted death. Review of the literature suggests this study can contribute to knowledge through a sociological perspective that illuminates *how* rights discourses have come to determine the end of life debate and policy, *when* and to *what extent* this may have occurred, and *who* the key actors are shaping the debate.

2.1 Challenging medicalised death

This section examines the current medical model of care and reviews clinical studies on assisted death. It critiques the changing nature of medical provision and the role of doctors to

determine care at the end of life. This sets the context for contemporary dying in the UK and highlights areas of controversy.

2.1.1 The medical model

The National Health Service (NHS) evolved in 1948 from a much deliberated but eventual cross party initiative that prioritised medical treatment for all, including the dying, free at the point of delivery and given according to need. Post WWII, individuals were encouraged to attend these newly established hospitals where medical equipment, services and skills were centrally located and could offer a standard of care that was not available at home. As a result of this, the majority of dying individuals were hospitalised and subject to a medical model of care that promoted the institutionalisation of death. The medical model traditionally embraced a patriarchal approach to healthcare where medical professionals diagnosed illness, sanctioned the most appropriate treatment and had the authority to determine when any prescribed treatment was withdrawn or withheld. In effect, the patient was dependent upon medical professionals to define their needs, give advice, decide how much information should be shared and then provide solutions (Bradburn 2003, House 2011).

This conception of healthcare where the doctor/ patient relationship assumed the patient as a passive beneficiary of care was accepted practice, both historically and in the context of a newly established healthcare system, but it has become increasingly contentious and subject to criticism. Death and dying, and the discourses associated with this, have traditionally been the remit of doctors and healthcare professionals who have expert knowledge articulated through specialised and exclusive language. However, the literature suggests their authority is being challenged on a number of levels. Foucault's early writing examined the exercise of professional medical knowledge under what he termed the "medical gaze" (Foucault, 1973). Rituals of the doctors' examination and decision-making processes under the medical gaze were criticised by Foucault (1977) for using techniques of an observing hierarchy and normalising judgement that included superimpositions of power/ knowledge relations. Foucault (1977), Turner (1995) and others argued that a medicalised model of care allows the medical profession and healthcare law and policy to dictate behavioural norms that deny individual liberty. Turner (1995) further developed this critique of the medical model to liken the practice of medicine to a form of social control, standardising different illnesses into

phenomena managed by bureaucratic agencies. For Turner (1995:153), the hospital represents a structure of authority symbolic of the social power of the medical profession, and the site at which contemporary political conflicts of an ideological, economic, and cultural nature occur. (Other aspects of Turner's contribution to the end of life debate are discussed below in a sociological context and in the following chapter in relation to developing a universal ontology of human rights).

A range of literature has evaluated the significance and development of the doctors' role in death and dying throughout the last century (Turner 1995, Walter 1994, Aries 1981, Foucault 1977). Alongside this, it has been noted that medical autonomy and status have diminished over the last two decades and this decline in medical authority challenges the practice of contemporary medicine (Elston 2009:17, Harrison and McDonald 2008:54). The hospice movement⁹ and organisations including Marie Curie and McMillan Nurses, have emerged in late modernity as alternative providers to fill the "gaps in NHS service provision", suggesting that the NHS lacks resources to provide a multidisciplinary, personally tailored approach to address the care needs of dying individuals (Harrison and McDonald, 2008:117). The increasing demand for hospice and community care¹⁰ reflects a "symbolic critique" of the medicalised, institutionalised death and an emerging desire to die according to personal values including physical, emotional and spiritual preferences at the end of life (Harrison and McDonald, 2008:117). The hospice movement strives to provide a comprehensive service and support to dying individuals and their families but critics suggest that, like the NHS, it has also been subjected to "routinisation" and "bureaucratisation". Hospices are beholden to economic and consumer forces, they receive 34% of their funding from Government and are therefore required to be accountable and transparent (James and Field, 1992 cited in Howarth, 2007:142).

⁹ The UK hospice movement was pioneered by Dame Cicely Saunders in the late 1960s to provide a holistic approach to death and dying and to address social, psychological, and spiritual aspects of care in addition to physical concerns (Harrison and McDonald, 2008:117). Motivated by compassion and her Christian faith in the sanctity of all human life, she established the first hospice, St Christopher's in London in 1967, with the conviction, "How we die remains in the memory of those who live on".

¹⁰ A report by the Dame Cicely Saunders Institute on public preferences for place of death in England, obtained from a population-based telephone survey in 2010, revealed the majority of deaths in 2010 took place in hospitals (53%) and only 21% died at home despite most participants across all regions stating that they would rather die at home if circumstances allowed (Gomez et al, 2010). Hospice was the second most frequent choice, especially in the South East and the East of England, where about a third of participants chose this, home and hospices together accounted for the preferences of at least 89% of participants in every region (Gomez et al, 2010).

The history and activities of the NHS have been widely discussed in the literature. In the six decades since its conception, the NHS has been challenged by frequent organisational change, fluctuations in the social and political environment, periodic scandal, huge financial cost and threatened collapse (Klein 2010, Doyal and Doyal 2009). The NHS and the medical profession has undergone major restructuring at regular intervals. Recent changes focus on user involvement and public accountability in an attempt to adhere to national strategic frameworks and targets but the priority increasingly rests on patient empowerment and satisfaction (Klein, 2010). Relevant to this research is Klein's (2010:166) observation that from 1991 onwards the NHS, in response to the ever-broadening demands, was defined by a period of adaptive policy with two new themes emerging, namely the health policy paradigm and the transformation of patients into consumers. NHS market mechanisms based on choice and competition developed inside state provision. These market forces reconstructed matters of health and illness as one's own responsibility promoting healthy lifestyles and encouraging members of society to be accountable for their own welfare and more discriminating in using NHS services (Kellehear 2008, Clark and Seymour 1999, Seale 1998, Turner 1995). The effects of this shift in government responsibility have been widely discussed from a sociological perspective (see Conway 2013, Howarth 2007, Schilling, 2003, Turner 1995, Giddens 1991, and Mellor 1993). Obligations and responsibilities are placed upon patients, including those who are dying, as individual and critical consumers and this endows them with the challenging task of negotiating their own lifestyle choices and validating these choices as important and legitimate.

The nature and extent of personal choice has developed over time and a Western notion of choice can be understood to encompass an individual's basic convictions, allegiances, life plans, objectives and moral principles, all of which contribute towards a sense of personal identity (Jennings 1996, Giddens 1991, Feinberg 1980). Borgstrom and Walter (2015) recently documented the concept of "choice" as the dominant rhetoric in government policy relating to end of life care and provision. Their study examined the comparative discourses of "choice" and "compassion" in UK end of life policy 2008-2014 and analysed the ways in which discourses of choice and compassion have become detached from each other. With reference to the End of Life Care Strategy 2008, the findings revealed, "the word compassion makes no appearance", but the use of "choice" appears 44 times in the 168 page document, referring most frequently to patient choice either directly or through programmes that support it (Borgstrom and Walter, 2015:100). This analysis of English policy discourse focused on how discursive power operates and argued that the government end of life strategy is clearly

designed to resonate with a neo-liberal political agenda that has divided the NHS into internal markets where patients and healthcare professionals exercise choice over buying and accessing services (Borgstrom and Walter, 2015:99-105). What has not yet been made clear, and needs further exploration, is *why* and *how* and particular discourses hold tenure over others.

Despite the emphasis on patient choice in government policy, the extent of choice has been criticised as inadequate. There is some degree of choice over *where* but not *when* end of life choice is realised, these choices are offered by powerful social organisations such as the NHS, The National Institute for Health and Care Excellence (NICE) or hospice providers but do not reflect real or unlimited citizen choice (Borgstrom and Walter, 2015). Providing an overview of policies and trends in patient choice, Milewa (2009:163) supports this analysis and argues,

...if the reality of choice is linked to ideas on an accentuated consumerist identity on the part of health service users, we need to be very clear about whose understanding of choice is being employed.

The comparative study by Borgstrom and Walter (2015) and arguments by Milewa (2009) revealed some interesting findings which suggest further enquiry into current end of life policy and legal provision is necessary to examine which discourses support a notion of actual and unlimited choice in end of life decision-making and the reasons for this.

Palliative medicine is ideally placed to conduct research in an end of life setting but the majority of studies in this field focus largely on pain relief as a priority of care rather than phenomenological accounts of dying. Research methods used often take the form of polls or surveys that cannot provide in-depth data to analyse the dying experience. Chen et al, (2014) recently surveyed 77 palliative care researchers using semi-structured interviews and identified five distinct impediments to research progress. These included:

...funding, institutional capacity, researcher workforce, challenges of the topic and population, public and professional misunderstandings of palliative care, and aversion to topics related to serious illness and end of life (Chen et al, 2014).

The dearth of end of life research in palliative care has also been explained by the priority given to direct care needs over establishing a research base, the skills of healthcare workers who may lack the time or interest in research and that hospices are often geographically situated away from academic or research institutions (Addington-Hall 2002, Field et al 2001). Most importantly, research on the critically ill is constrained by rigorous ethical frameworks and gatekeeping by medical ethics committees (Addington-Hall 2002, Field et al 2001).

The apparent lack of palliative care research conflicts with a growing awareness and discussion of dying in the public sphere and the growing emphasis on developing a framework of care to manage expectations of “patient centred” dying and improve end of life care (Bradburn 2003, Clark and Seymour 1999). The development of alternative research methodologies that comprehensively elicit the needs of the dying is suggested as an important yet neglected area. This finding stimulated interest in the expectations of “patient centred” and public perceptions of dying well and prompted closer analysis of the discourses that are defining the end of life. A sociological exploration of these discourses to discover how they arise and operate in a contemporary social context could inform end of life healthcare policy and practice.

2.1.2 Clinical studies on assisted death

Trends in polling data and academic studies on doctors’ role and attitudes have confirmed the overall negative stance of professional medical bodies and general lack of support among healthcare practitioners towards assisted dying with doctors working in geriatric or palliative care medicine most likely to oppose the practice (McCormack et al 2012, Seale 2009). Based on their medical knowledge, doctors would be the natural choice to provide the practical means for an assisted death. The relationships they form with their patients would enable competent assessment of whether requests for assistance to die were expressed as a rational choice. However, all of the major medical bodies remain opposed to the participation of doctors in the practice of assisted death. Medical literature notes assisted death to contravene the traditional “care over killing” philosophy of the medical profession. Such opposition is articulated clearly by the British Medical Association (BMA) position, which recently stated that permissive reform was “contrary to the ethics of clinical practice as the principle purpose of medicine is to improve patients’ quality of life, not to foreshorten it” (BMA, 2012). There is, however, careful acknowledgment by healthcare professionals that the practice of assisting death, in circumstances where doctors act in the best interests of the patient, does occur. The most direct indication of this was revealed in a study by Professor Clive Seale (2010) who has extensively researched the attitudes and practices of doctors at end of life. He discovered a “*significant minority*” of UK doctors reported making decisions they think will hasten the death of a patient and that non-religious doctors were more likely to report decisions taken with some degree of intent to end life, or provide continuous deep sedation leading to death, suggesting that the practice of assisting death does occur (Seale, 2010:677).

Systematic review of the international literature by Hendry et al, (2013:13) examined the views of patients, carers and the public on assisted dying to reveal that attitudes were diverse and complex but confirmed that in general “[p]eople valued autonomy in death as much as in life”. The majority of clinical studies suggest that concepts of personal autonomy and human dignity are prioritised at the end of life. There is general concern for the loss of autonomy and dignity in dying and whilst suffering is a factor, requests for assisted suicide are driven primarily by fear; fear of pain, fatigue and loss of function that can lead to dependency (Ganzini et al 2008a, Pearlman et al 2005, Mak and Elwyn 2005, Pacheco et al 2003, Emanuel et al 1996, Chochinov et al 1995). The Oregon-based study by Ganzini et al (2008a) surveyed family members who had experienced a recent bereavement of loved ones due to an assisted death. Reasons cited for the deceased having chosen the legal option of assisted death were: the desire to control the circumstances of their death including the option to die at home; concerns regarding loss of dignity and future losses of independence; quality of life, and self-care ability (Ganzini et al, 2008a). Deceased individuals had regarded the actual physical symptoms of their illness as less important compared to future worries about the severity of symptoms (Ganzini et al, 2008a).

Concern for an undignified death was also cited as a factor that could provoke requests for assisted death. Chochinov et al (2002) noticed that clinical studies had documented a loss of dignity as reasons for requesting an assisted death in 50-60% of cases and on this basis attempted to design an empirical model to understand how concepts of dignity were defined and understood by dying patients. The study revealed a strong correlation between a sense of dignity and autonomy in control over life events. This was primarily centred on self-identity rather than functional ability (Chochinov et al, 2002). This is an important finding that has not yet been further developed and has implications in relation to this research question. How, when, and to what extent, have concepts of autonomy and dignity that can also be understood in terms of human rights, become so highly esteemed in an end of life context? Review of the medical and clinical literature in this section demonstrates that both of these concepts feature prominently in the contemporary discourses of death and dying. Notably dignity and autonomy are also important components of a human rights approach. However, studies have neglected to examine this relationship in-depth or investigate the potential implications, outcomes or meaning of this relationship.

2.2 Determining the good death

This section examines the status of death and dying within the current social context. A nationwide decline in religiosity is demonstrated. This, among other factors, has left individuals with an increased responsibility for negotiating their own lifestyle choices and these are subject to prevailing discourses that, at present, emphasise liberty, dignity and a desire to avoid suffering and to achieve what is considered a good death. The findings suggest closer exploration of the discourses that relevant social actors use to express and support their positions in an end of life context is necessary.

2.2.1. Death as taboo

A range of literatures, particularly in the second half of the 20th century, noted that death had become more withdrawn from public life, and the experience of dying gradually privatised, subjectivised and more individualised (see Howarth 2007, Turner 1995, Mellor 1993 and Aries 1981). Mellor (1993) suggests death has been “hidden” in late modernity. He argues that an increasing sense of self-identity relating to the body and “shrinkage in the scope of the sacred” have privatised experiences of death that now occurs as an event absent from the public domain (Mellor, 1993). Hospitalisation could be argued as a compassionate response to provide optimal treatment or protect the dying individual and their family from the care-giving burden of their situation, however, by removing the dying person from their community and family environment the mystery surrounding death is perpetuated and it becomes a less visible or “taboo” subject (Walter 1991, Aries 1974). Taboo subjects are less commonly spoken of in public and private and in this respect are likely to remain *status quo*. Bringing end of life issues into the public arena means that they become susceptible to a range of influences and discourses, which can shape or potentially change, existing attitudes.

Walter (1994) and Seale (1998) contest death as a taboo or hidden phenomenon on the basis that public interest in death and dying has increased. This is evidenced by frequent discussion of NHS plans, marketing of life insurance sales, pre-paid funerals and media coverage of death. An interest in death is also apparent in the extent and variation of its graphic representation in plays, books, art and the media (Copp, 1999:1). At national level, the Dying Matters Coalition are encouraging people to speak more openly about, and plan for, end of life in general. Privately funded initiatives including Death Café and Death Salons are now deliberating the topic of death and dying in the public domain (see Dying Matters 2015, Dignity in Dying 2016 and Death Café 2014). The media has been instrumental in raising public awareness of assisted death as an issue discussed in terms of rights, not only through coverage of emotive legal

appeals and individual accounts that request a “right to die” but also through bringing the Parliamentary debates into the public consciousness and highlighting the arguments of high profile individuals. The idea of human rights in an end of life context has recently been taken up by the British Institute of Human Rights. Their research included the publication of *End of Life Care and Human Rights: A practitioner’s guide*, a document aimed at providing accessible information on human rights to healthcare practitioners to support them in delivering care services with respect for human rights (BIHR, 2016).

2.2.2 Religious and cultural influences

A range of literature has noted the decline of religious affiliation, practice and belief in the UK over the past several decades, arguing that religious influence and religiosity has fallen (Danyliv and O’Neill 2015, Bruce 2013, Voas and McAndrew 2012). Traditional religious and community frames of reference that give some indication of normative values have become weakened. This now leaves individuals to negotiate and validate their own lifestyle choices within the prevailing social discourses (Schilling, 2003, Turner 1995, Mellor 1993, Giddens 1991). Religion traditionally provided a source of self-identity, enabling individuals to locate their chosen practices within an affirmed set of moral values and UK attitudes towards death and dying have been primarily influenced by a Judaeo-Christian perspective. From this religious position, human beings are created by and are at the mercy of God who has dominion over both life and death. Divine approaches condemn suicide and assisting suicide as immoral, and arguments grounded in a Judaeo-Christian tradition are mostly centred upon respect for the inherent sanctity and worth of all human life (Jeffrey 2009, Keown 2002).

Research on patterns of religious affiliation, practice and belief revealed a confusing and limiting picture. Danyliv and O’Neill (2015) used the British Social Attitudes Survey to explore changes in attitudes to the legalisation of physician assisted death over the period 1983-2012 in association with religious belief. They discovered that, perhaps as expected, increasing support for assisted death did correlate with an increase in secularisation (Danyliv and O’Neill, 2015). Ho and Chantagul, (2015:273) examined a number of studies and also found significant differences between believers and non-believers in attitudes towards the legalisation of assisted death. However, their research also discovered that while some studies found religious groups to be largely against assisted death, others contested this. These studies suggested instead that a majority in these religious groups favoured legalisation, or were

prepared to assist themselves. Conflicting findings suggested a complex and variable relationship between religion and attitudes towards assisted death.

Trends in research on religion from a Judaeo-Christian¹¹ perspective suggest that UK society is becoming “progressively more secular as each generation emerges” (Voas and McAndrew 2012:46). The boundaries between life and death have become blurred by advances in medical technology that can prolong life. Given the changes in the dying trajectory which sees individuals living longer with chronic illness, it has become less clear who controls the dying process, under what conditions death should, or could, occur, and which criteria are used to determine a good death. Religious and cultural frames of reference are losing traction. In regard to culture, Seale and Van der Geest (2004:883) noted “considerable cross-cultural variation in patterns of disease, demographic factors and cultural norms that influence the experience of death, dying and grief”. Personal autonomy, freedom of choice and human dignity are indicative of contemporary, secular, Western values at the end of life (Seale, 1998) but these values may not be common to all and can be disputed from other religious, cultural or personal perspectives. Koenig and Gates-Williams (1995:249) argue

The cultural values and beliefs that inform the new bioethics practices are white, middle class and based on western philosophical and legal traditions that emphasise the individual and individual decision-making. Successfully implementing “death by decision” depends on a set of cultural attributes including the open disclosure of distressing information, the desire for control, and future orientation, described elsewhere as the “autonomy paradigm”...

Experiences of death and dying in the UK seem to focus on individual liberty and choice. These concepts have also been articulated by some social actors as constituents of a “good death” that is an emerging focus for study (see Pierson et al 2010, Seale and Van der Geest, 2004, Carr 2003, Steinhauer et al 2000, Hart et al, 1998).

2.2.3 The concept of good death

A key trend in recent research has been to establish what a “good death” entails. Both clinical and academic disciplines have evaluated personal priorities and preferences at the end of life in an attempt to illuminate the concept of dying well. Despite this, a good death in

¹¹ The role and attitudes of other religions than Judaism and Christianity in the end of life debate and policy is largely absent, even though data from the Office of National Statistics in 2001/2011 record sizable populations of Muslims, Hindus, Sikhs and Buddhists. Reasons suggested for the absence of correlative studies on other religions are not apparent but may have to do with the differences in behaviours and practices that characterize other religions (Bruce, 2013:376).

contemporary society remains difficult to define and is highly individual depending on a range of influences (Kemp, 2002:4). Hart et al (1998:71) argue a good death in late Western modernity emphasises the value of meaningful, personal activity at the end of life that could include adjustments to and preparation for death, relinquishing of roles and responsibilities, and the opportunity to take leave of loved ones. Steinhäuser et al (2000) conducted focus group discussions with participants who identified six major components of a good death, these included, “pain and symptom management, clear decision making, preparation for death, completion, contributing to others, and affirmation of the whole person”. Research by Carr (2003) also found a good death to be enhanced by “physical comfort, social support and good medical care”. In addition, Seale and Van der Geest (2004) proposed that in more affluent societies, a good death ideally occurs at home with family and friends, at the end of a long and fulfilled life where wealth is accrued and children raised, culminating in an appropriate funeral ritual.

Expectations surrounding death are determined by cultural and religious negotiation, social factors, personal circumstances, prior experience, and discourses that shape attitudes at the end of life. The literature suggests that individuals generally aspire to die in a manner consistent with their own coping mechanisms and in relation to their own values and beliefs in a death and life context (Dunlop 2007, Gustafson 2007, Smith 2000). Quests for a good death attempt to maintain individual priorities and a sense of personhood in the dying process, supporting concepts of human agency and autonomy in regard to decision-making. Discourses that respect individual liberty and human dignity could potentially enhance the aspiration of dying well or dying a good death and this may be one reason for their increasing popularity.

Choice

Very few academic studies have addressed the concept and boundaries of personal choice in end of life decision-making directly. Burchardt et al (2014) critique a failure to conceptualise, measure and analyse the intrinsically valuable aspects of choice and claim this leads to inequalities in the opportunities people have to exercise control over important aspects of their lives. Auerbach, (2001: 191-203) examined the extent of patient involvement in their own care to find that, whilst there was a strong desire for information during illness, there was less interest in taking decisional control at the end of life. Instead patients prioritised collaboration with medical professionals. Individual choice may be intended as a tool to improve effectiveness and economy in service provision and involve the dying in self-management of

their conditions, but literature highlights that the concept of choice is not commonly understood.

In complex and sensitive matters including end of life decision-making, Thorns (2010) proposes there is a key distinction between respecting *autonomy* and respecting *personal choice*. Elaborating upon this difference, Thorns (2010) suggests that the notion of personal autonomy does involve elements of choice and decision-making within a clinical setting, however mere choice may be an inadequate and non-conducive framework for supporting individuals at the end of life. He uses a practical example to illustrate this point. By directly asking a person “Would you like to die at home?” they are offered a choice expressed as a personal preference. In contrast, respect for autonomy encompasses and recognises aspects of human agency and rational free will. This is demonstrated when the implications and consequences of this decision are explained, and time is taken, to ensure a person has the capacity and understanding to acknowledge these (Thorns, 2010). Differentiating between autonomy and choice involves making an informed and rational decision based upon freely given and relevant information, rather than a mere preference. This is especially important in an end of life context.

To respect individual models of autonomy and ensure the patient/ personal narrative is not neglected in a wider social context involves recognising the complexity of end of life decision-making in a socio-cultural environment where interpretations of morality and ethics differ (Ingleton et al, 2013). Nordgren (2010) commented on the emergence of freedom of choice in healthcare as serving to reconceptualise the notion of patients as a self-determining participant in the management of life and death constructing this participation as a democratic and personal “right”. The reconceptualisation of choice aligned with human rights discourses through understandings of personal liberty and human freedoms could suggest a new perspective on end of life that could influence the terms of the debate. This drives forward the research interest in determining how autonomy and choice can be grounded in frameworks of rights and the extent to which these different perspectives can be used to conceive and support a right to assisted death.

Dignity

There is recent focus in the literature on concepts of dignity that are widely promoted as desirable in end of life care. Achieving a *dignified* death is increasingly expressed as indicative of a good death. Gennip et al (2013a) surveyed 163 family caregivers of deceased older adults where 69% were of the opinion that their family member had died with dignity. Contributory factors that supported their personal interpretation of a dignified death included: the patient feeling ready to die; the absence of anxiety; that they were fatigued, and that doctors had provided a clear explanation of treatment choices at end of life (Gennip et al, 2013a). This study, perhaps surprisingly, revealed that symptoms not significantly related to conceptions of dignity or associated with a good death included the (primarily) physical symptoms of pain, breathlessness, incontinence and reduced physical ability (Gennip et al, 2013a). Further study by Gennip et al aimed to develop a conceptual model of dignity to illustrate how serious illness could undermine patient dignity. They discovered that illness affects dignity indirectly by affecting the way in which patients perceive themselves and that this self-perception is shaped by three components. These involved: the individual themselves, based on the subjective experience and internal qualities of the patient; the relational self, based on reciprocal interaction with others, and the societal self, based on their experience as a social object from another's perspective (Gennip et al, 2013b). Dignity is an important principle in end of life care, the maintenance of dignity and avoidance of indignity is highly prioritised among the dying and their loved ones. However, dignity in dying is subject to interpretation and influenced by personal values, backgrounds and experiences. What one person deems as dignified may be undignified for another.

The status and protection of human dignity reflects a central issue in human rights. There are newly emerging areas where research is being conducted on concepts of dignity and choice that encompasses concepts of rights. Nordgren (2010) questioned the development and extent of freedom of choice as part of a healthcare discourse and Jacobsen (2009) referred to the Universal Declaration on Human Rights 1948 to define a taxonomy of dignity and establish dignity as a link between human rights and healthcare. The notion of choice is frequently coupled with dignity in the context of dying using rights as the common basis for this association, as in this example:

...the right to choose¹² is a basic expression of one's dignity and there is no more fundamental expression of one's dignity than the right to make life-saving or life-terminating choices (Beyleveld and Brownsword, 2001:242).

¹² Where the extent of individual freedoms are debated in an end of life context, choices that reflect individual liberty and human agency are expressed by a range of social actors as a *right to choose*. This

In the dying process, conditions that further genuine self-respect and enhance dignity of the dying experience are often reciprocally linked with autonomy. For example, Paust (1995:480) connects autonomy with notions of dignity at the end of life claiming “When quality of remaining life would reek of indignity and suffering, it is all the more appropriate to respect the dignity of personal choice”.

Extensive research on assisted death by Battin (1994:12) draws closest to situating the end of life debate within a normative framework of rights claiming that the issue is one of “civil liberty”. Individuals in a democratic society should have the *right* to determine their own death. She also suggests that assisted suicide arises in response to the standardisation of medical care, so that when self-identity and human agency are threatened, the desire for self-determination increases. Writing on the relationship between suicide and rights, Battin (1994:279) argues this is a “fundamental human right” that equates with the right to life, freedom of speech and belief. Her understanding is that individuals have certain rights that are conducive to human dignity. This existing research is helpful but does not adequately explore concepts of choice and dignity within conceptual frameworks of human rights, nor offer any suggestion to how a right to die may be conceived. Examining different positions on human rights to understand how or why issues at the end of life use rights discourses or come to be articulated as rights has not yet been addressed.

Suffering

Achieving a dignified or good death can be challenged by the experience of serious illness, especially in circumstances involving unbearable or protracted suffering. Against the backdrop of current medicalised models of care that perpetuate a longer dying trajectory, the experience of human suffering may lead some individuals to contemplate ending their lives prematurely. Kellehear’s (2009) literature review finds suffering characterised as a series of explanations about distress rather than a single concept. His general perceptions are that some loss due to pain, injury and/ or deprivation occurs but this is usually time and culture specific. The work of Kohn and Steeves (1996) supports the position that suffering is relative: it is a unique, private lived experience. There is no standardised empirical tool of measurement that can assess personal interpretations of suffering so that it can only be defined as an

articulated right to choose is not legally binding, but is constructed and substantiated as a reflection of inherent personal autonomy and human dignity, the reasons for and implications of which are considered further in section 3.2.2.

“individual experience of threat to self and meaning given to events such as pain or loss” (Kohn and Steeves, 1996). That said, their extensive ethnographic research finds that all suffering has basic structural elements. These include: disruption of human experience; an altered sense of embodiment; a constricted social world in relation to others and the lived space, and a changed perception of time (Kohn and Steeves, 1996).

Dees et al (2011) conducted a study involving 31 face-to-face interviews with individuals who had requested assisted suicide in order to explore how suffering had contributed to their requests. They found that suffering comprised medical, psycho-emotional, socio-environmental and existential themes. In particular

...fatigue, pain, decline, negative feelings, loss of self, fear of future suffering, dependency, loss of autonomy, being worn out, being a burden, loneliness, loss of all that makes life worth living, hopelessness, pointlessness and being tired of living were constituent elements of unbearable suffering (Dees et al, 2011).

Suffering was found to be the outcome of an intensive process that originates in the symptoms of illness and/or ageing and the burden of suffering was influenced by individual personality characteristics and backgrounds (Dees et al, 2011). Concepts of suffering were dependent on the patients' perspectives of the past, the present and expectations of the future and in this way relate to a social and cultural context¹³ (Dees et al, 2011). Human suffering may be an authentic and generally accepted reason to justify requests for assisted death. Actual or anticipated suffering has the potential in some individuals to shape the end of life decision-making process and prompt requests for assistance to die. However, achieving consensus on what constitutes suffering *is* difficult and particularly subjective. It is dependent upon individual and variable perceptions that necessitates deeper investigation of death and the circumstances of dying as a social construct.

2.3 Constructing assisted death

¹³ Suffering is not always viewed negatively. Penn and Malik (2010) highlight that evolutionary theory, psychology and other schools of thought claim suffering is necessary for human development. Suffering arises with a consciousness of disparity between the current state and future desired state and this acts as a motivator driving human development. Badham (1996:109) comments that Christian doctrine attributes value to enduring suffering with patience and endurance believing this may provide time and opportunity for spiritual growth of the dying individual. It may also be plausible to suggest that a protracted period of illness enhances the notion of a good death by allowing family and friends a time for reconciliation including the opportunity to care for the dying person, facilitating the process of saying farewell and taking leave of the community in which they have participated.

This section explores how rights may arise and become embedded at the end of life from a sociological perspective. The role of social actors, including the media and new social movement organisations, is discussed in relation to how or why they employ particular discourses to define and promote specific issues.

2.3.1 Actors in the debate

Mainstream UK media including national, regional, and local newspapers and the British Broadcasting Corporation (BBC) television news has extensively covered the end of life debate. There is a wide body of literature on the impact and ability of the media, civil society organisations and new social movement (NSM)¹⁴ actors to affect the institutionalisation of rights through the use of *framing* techniques (see Miller 2010, Campbell 2006, Stammers 1999, Byrne 1997, Seale 1998, Snow and Benford 1992). Chong and Druckman (2007:99-118) elaborate that the major premise of framing theory is that an issue can be viewed from a variety of perspectives and be construed as having implications for multiple values or considerations. Framing refers to the process by which people develop a particular conceptualisation of an issue or reorient their thinking about an issue (Chong and Druckman, 2007:99-118).

Use of the media is an effective method of reaching a large audience, promoting awareness and bringing the debate into the public arena (Dalton, 2007:64). Media representation of high profile right to die cases through their graphic, heartrending testimonies have a “symbolic potency” in the public imagination, their suffering has been imbued with moral and political meaning (Richards, 2014). A 2006 study by Birenbaum-Carmeli et al (2006:2153) typified UK media coverage of family assisted suicide through newspaper articles that examined court cases in which a family member had been charged with assisting suicide. Their observations revealed

...a consistently supportive stance towards family assisted suicide that is produced by depictions of dying persons and perpetrators as autonomous and conscientious individuals; by idyllic portrayals of family relations; and by praising judges for their

¹⁴ In contrast to traditional social movements, NSM’s generally arise from middle class initiatives and focus on cultural change enhancing personal/civil liberties linked with identity. They tend not to desire political power or stem from economic grievances (Byrne 1997: 48). Stammers’ (1999:984) definition of an NSM that is indicative of the right to die movement involves

Collective actors constituted by individuals who understand themselves to share some common interest and who also identify with one another, at least to some extent.

lenient verdicts. Presentations of the law as a dated State system, as well as the marginalization of opposing voices, further enhanced the supportive message (Birenbaum-Carmeli et al, 2006:2153).

Social anthropologist Naomi Richards has studied media coverage of “right to die celebrities”. Her research focused on the reach of the media in shaping public attitudes towards assisted death where she argued

...the commodification of experiences; the instrumentalisation of suffering, all of which may have a significant impact on the ‘national mood’ when it comes to the social sanction of deliberate death (Richards, 2014:17)

The media are also a major public forum for claim-making by social movement activists (Richards, 2014:17). Through the use of strategic framing, the media, civil society organisations and new social movement actors render the issue of assisted death relevant, determine how it will be discussed from an ideological perspective, identify who is accountable and promote strategies for achieving potential solutions (Birenbaum-Carmeli et al 2006, Seale 1998, Snow and Benford 1992). It is important to acknowledge that, as social actors, the media have influenced the current debate by featuring heartrending individual cases, asking key questions, highlighting support from a range of sources, and framing the issue as a *right* to die. However, the role and rhetoric of the UK media in the end of life debate is not the focus for this thesis. Other academics are pursuing this line of research.¹⁵

As the topic of death and dying moves into the public arena, commonly termed “right to die” organisations become instrumental in generating public interest and constructing specific discourses to frame the end of life debate. There is a World Federation of Right to Die Societies (WFRtDS) that consists of 52 right to die organisations from 26 different countries. Their purpose, articulated specifically in terms of rights, is to provide “an international link for organizations working to secure or protect the rights of individuals to self-determination at the end of their lives” (World Federation of Right to Die Societies, 2015). In the UK, there are two main organisations that are actively campaigning in support of assisted death for terminally ill, mentally competent people, Dignity in Dying, (DiD) and Friends at the End, (FATE) based in Glasgow. In contrast to FATE, DiD are not full members of the World Federation, but listed as

¹⁵ Medical sociologist Professor Clive Seale is currently developing computer software that can analyse large portions of text to explore media coverage of the right to die over time. Dr Naomi Richards is investigating from an anthropological perspective the role of media coverage of right to die cases in contributing to the “national mood” on assisted death.

an affiliated organisation.¹⁶ These organisations share a common understanding of human rights that includes exercising individual liberty to determine the manner and timing of their death, especially in circumstances where suffering could prevent a dignified death. But what is not apparent, is how or why rights discourses appear to hold traction in this context.

Right to die organisations promote concepts of autonomy/ choice, dignity, rights and suffering. These generalised values can also be understood as human rights principles encompassing “individual choice, liberty rights, privacy¹⁷ and freedom of the will” (Beauchamp and Childress, 2001). Gibbs (2007:60) proposes that discourses with which social movement organisations choose to communicate their objectives can be a powerful tool used to influence the way that people think about, and give meaning to, their interests and is often used to “help groups define an issue or their collective stance towards it”. Miller’s (2010) contribution supports this. She argues (albeit in the context of development) that campaigning organisations use human rights frames for strategic purposes. “Rights-framed approaches” as developed by Miller (2010) are used as a way to serve the ideology of the organisation by repackaging ideas and beliefs to promote and advance the campaign objectives. Miller’s (2010) contribution is explored further in section 3.2.2, her findings are also used to develop the case study analysis of the campaign for Dignity in Dying in Chapter 7.

Review of the literature exposes a lack in analysis of the framing techniques and campaign strategies used specifically by right to die organisations or civil society organisations promoting the right to die. Two studies have been conducted to date, both on FATE.¹⁸ Judd and Seale (2011) distributed questionnaires to FATE members for the purposes of obtaining a

¹⁶ Email correspondence with the President of the WFRtDS, Rob Jonquiere, to question this status revealed that DiD had strategically reconsidered their association with the World Federation in order to reduce controversy and resistance to furthering their own objectives in the UK. He provided this explanation:

Dignity in Dying used to be a member of the WFRtDS, but decided they ‘had to’ quit a couple of years ago because they did not want to be associated with a Federation that was presided by someone active in organisations that propagate Do It Yourself (DIY) methods. They consider such activities as damaging to their objective and lobby, especially-as I understood-because of damage being caused by media when they...discover this association (Jonquiere, 2015).

¹⁷ The concept of privacy, both in terms of healthcare and human rights has been largely under-theorised. It is addressed briefly in the following chapter and emerges in this research findings mostly in regard to the legal petitions of Diane Pretty and Tony Nicklinson discussed in section 5.2.

¹⁸ FATE, as an organisation, was not selected for in-depth analysis in this research. It does provide a befriending function that accompanies dying individuals to Dignitas but in comparison to Dignity in Dying it has fewer members and resources and has been less significant in shaping the public and political debate.

demographic profile of these members to gain insight into their individual values and beliefs and their motivation for joining the organisation. Thirteen percent of individuals stated that their reasons for joining FATE revolved around concepts of *rights* in that they thought it a fundamental right to decide the manner and timing of death or to die with dignity (Judd and Seale, 2011:232). The second study by Naomi Richards investigated older people and death activism through interviews with members of FATE. She discovered the primary motivation of FATE activists involved “fear of a protracted dying period in which the fragmenting of social bonds and loss of sociality would precede death, entailing a loss of personhood” (Richards, 2012:11). These studies contribute to understanding the appeal of assisted death and the motivation for joining a right to die organisation, but do not address the discourses with which the organisation frames its aims to define the issue of assisted dying. The finality of death, the variation in the dying trajectory, personal experience, social relations, cultural values and religious beliefs highlight specific dilemmas that organisations in support of a legalised assisted death encounter. This emphasises the necessity of framing their objectives within widely agreeable discourses.

2.3.2 A sociology of rights

Findings of the literature thus far demonstrate that research has been conducted into areas of death and dying to locate this in a contemporary UK context, to determine what is important to dying individuals, and to evidence how concepts of liberty and dignity including relief of suffering have been prioritised. However, the issue of assisted death articulated as a *right* to die has not yet been a focus for sociological study. The earlier work of Professor Bryan Turner raised the critique that sociology had not engaged sufficiently with normative theories of rights. He argued that

Human rights debates and legislation are major features of the socio-political processes and institutions of modern societies, but sociology apparently possesses no contemporary theory of rights (Turner, 1993:490).

Turner theorised that a concept of human rights could be located within a sociology of the body, particularly in regard to human vulnerability. This could be understood from a sociological perspective through a need for provision in social institutions to protect this vulnerability (Turner, 1993:502). His contribution grounded a sociology of the body in a social context of action and reciprocity and argued that human beings are subject to a diverse range of threats and influences, including those from the institutions that are designed to protect them (Turner, 1993:502). Vulnerability of the body as a universal concept forms the basis for Turner’s “frailty theory of human rights”. This is discussed in depth in the following chapter.

The experience of human suffering and an understanding of universal vulnerability are important in an end of life context and Turner's frailty theory of rights could be valid where individuals are at the mercy of their impending mortality and the institutions that define end of life provision.

Short (2009) noted the reluctance of sociology to engage with, and develop, an analysis of rights that was due to a widespread preoccupation by the discipline with the concept of citizenship. In an increasingly globalised world, nation state sovereignty is challenged through international mechanisms. Issues arise that are not necessarily confined to the nation state and this motivates an interest towards analysis of *human* rights in a broader and universal context rather than *citizens'* rights solely in relation to a nation state framework (Short, 2009:95). There is fast-growing interest in the sociology of human rights¹⁹. Issues expressed in the language of human rights have become a more prominent feature of the social and political landscape and this approach to rights enables complex claims to be analysed in the context of social power dynamics. Contemporary interpretations of rights centre upon the struggle for emancipatory change and, in an end of life context, the balance of power is between individuals who demand a right to die and the institutions that enable or constrain this.

Where sociology had previously limited an analysis of rights to the realms of citizenship, anthropology had traditionally examined non-Western, "primitive" societies and had difficulty reconciling a concept of universal rights with their ethnographic approach, which involved studying diverse cultural difference (Short, 2009:99). Emerging trends within sociology and anthropology suggest these disciplines are now engaging with concepts of rights through a shared social constructionist approach that can help understand how rights operate in a social context. This approach can be used to analyse rights claims as the product of social processes. Lydia Morris argued that a social constructionist perspective on rights should be adopted to better inform

...how rights come into social being and operate in social practice, whose purpose they serve and what interests they protect and whether they are guaranteed or constrained by the practice and letter of the law (Morris 2006:7).

¹⁹ Demonstrated through the work of Frezzo (2014), Hynes et al (2012, 2011, 2010), O' Byrne (2012), Miller (2010), Short (2009), Morgan and Turner (2009), Morris (2006) and, also, in 2007, through the formation of a new study group by the British Sociological Association to bring together people interested in promoting the sociological study of rights (School of Advanced Study, 2016).

The contribution of anthropology towards understanding the social practices of rights was instigated through the work of social anthropologist Richard Wilson. He argued that the earlier focus on rights assumed them to exist purely within a legal domain and had neglected to examine the “social life of human rights” (Wilson, 2006). This is indicative of the end of life debate. There are laws and policies in place to determine normative behaviours and practices at the end of life, but the process and experience of dying is a social, rather than legal, phenomenon. On this basis, it warrants deeper sociological exploration. Wilson’s contribution emphasised the social nature of rights. He distinguished between emphasis on the legal nature of rights and “human rights talk”, addressing the analytical import of the way social movements construct and deploy rights discourses to interpret particular issues or interests, and to determine “how people speak about those norms or aspire to expand or interpret them in new ways” (Wilson, 2007:350). O’Byrne, like Wilson (2007) emphasised the necessity of understanding rights within a sociological context. He argued “competing voices contest the ownership of this language and this discursive struggle is a profoundly *social*, not a *legal* process”(O’Byrne, 2012:831).

Theorising the language-structure of human rights, O’ Byrne (2012:835) argued that human rights may be considered a legitimate framework within which individual claims can be made in so far as the “language of human rights provides us with a set of ethical validity claims which we as individuals and on behalf of ourselves and others make against society as a whole”. The value of “rights talk”, utilised in conjunction with political discourse, has been noted and this may be driven by the activity of social movement organisations and moral reformers using rights discursively as a tactic to assert the existence of real or imagined rights (O’ Byrne 2011, Miller 2010, Wilson 2007, Freeman 2002, Douzinas 2000, Glendon 1991). Liberal conceptions of personal freedoms and self-determination, expressed through rights discourses, suggest that individuals acting with rational capacity should be able to determine the manner and timing of their own death. A right to die may be articulated *explicitly* as such, or *implied* through understandings of rights that involve personal autonomy, dignity, relief of suffering and vulnerability.

Particular discourses develop over time. This is an important finding in the literature that may help explain how the expression “right to die” has come to be used and to what extent, and for what purposes, concepts of rights are now being invoked in the end of life debate and policy. The ways in which social actors articulate their needs and priorities in relation to the end of life

has implications for how society thinks about, and gives meaning to, the experience of dying. Closer analysis of how and why rights discourses are employed by a range of social actors in an end of life context is necessary. This is an area that has been neglected by the existing literature. A sociological approach to rights struggles, discourses and practices can help identify how issues come to be expressed in terms of rights and how rights claims arise and become embedded in new contexts.

Conclusion

This chapter has demonstrated that assisted death, on occasion expressed as a *right to die*, is a contemporary and complex issue that has arisen due to changes in the late modern, Western dying trajectory. The established medicalised model of care, which has defined end of life since the latter half of the 20th century, has been challenged by an increase in healthcare consumerism and a shift in state responsibility in favour of individual accountability for matters of health and death. Concepts of choice and dignity are being prioritised. These values were reiterated as important at the end of life through review of clinical studies on assisted death. Notions of a good death have developed and, although this is subjective, a well-managed death generally involves limited suffering and a respect for individual personhood and values. The prevailing discourses that appear to characterise the dying process in the UK and the understanding of a good death currently involve notions of liberty and dignity. These are also integral to human rights discourses.

This chapter has revealed that discourses involving individual liberty, dignity, and relief of suffering are increasingly defined as important. However, while a number of disciplines are researching end of life there is no sociological analysis of why assisted death has come to be expressed as a right to die, or how and for what purposes social actors interpret rights in an end of life context. Reviewing the literature has revealed the “social life” of rights at the end of life as a particularly interesting focus for study, and an area that has not yet been addressed. The understanding and appropriation of rights discourses in this different area is especially important because these discourses may resonate with current values, generate public support, and facilitate change so that different ideals become institutionalised. An understanding of rights at the end of life that includes new sets of rights claims has the potential to transform social norms. To comprehend how a notion of *rights at the end of life* could arise and become embedded in practice, greater clarity is needed regarding how, for what purposes, to what extent, and by whom such discourses are employed. This research will

complement the work of other end of life scholars who have not yet considered the impact of rights discourses in the context of death and dying and existing research into a sociology of rights that has not yet studied rights in an end of life context. The findings in this research will enable a sociological understanding of rights to be developed in a new context. On this basis the study will contribute to

...the growing strength and diversity of analyses in the sociology of human rights, characteristically moving away from a static and foundational view towards a more dynamic and critical analysis of the contested linguistic, normative and geopolitical content and parameters of human rights discourse and practices (Hynes et al, 2012:790).

Human rights frameworks are examined in the next chapter to illuminate different positions on rights that social actors may adopt when they articulate their interpretations and understandings of rights. Concepts of personal liberty, human dignity and vulnerability of the body are explored and embedded as human rights discourses. The following chapter will include foundational and anti-foundational perspectives on human rights to demonstrate how these approaches may be utilised in an end of life context and how, as a result of this, a right to die may possibly be conceived. These frameworks will reveal positions on rights that may subsequently be identified in the data as it emerges.

CHAPTER 3

Human rights frameworks

What is meant when a “right” to something is expressed? It appears the interpretation and application of human rights vary according to whom is articulating rights and, as Dembour (2010:2) argues, “[d]ifferent people hold different concepts of human rights”. The purpose of this chapter is to explore the ways in which human rights could be understood, demonstrate how rights discourses can be appropriated in an end of life context and, as a result of this, explain how a right to die may be envisaged. This chapter contributes to the research by illuminating perspectives on rights and clarifying positions from which various arguments can be made when different actors articulate issues at the end of life using the language of rights.

This chapter is divided into three sections. In the first section, a foundational position on rights is discussed. Within this perspective, the right to an assisted death can be grounded in conceptions of fundamental and innate personal liberty and human dignity that could explain or validate end of life decision-making. Turner’s “Frailty theory of human rights” is included here to support a foundational ontology. This is particularly poignant with regard to the vulnerability of dying individuals and those contemplating death. The second part of this chapter explores an anti-foundational position, which rejects the foundational assumptions of human rights, arguing instead that they are time and context specific. An anti-foundational

paradigm encompasses both a legal approach to rights and a social constructionist approach. Legal positivism includes examination of the role of the nation state that, from this perspective, is considered important for the recognition and protection of the human rights of its citizens. Social constructionism is explored in relation to how new social movement organisations use discursive strategies to influence how an issue is thought about and to help realise their objectives. In contrast to what has commonly been referenced as “rights-based” approaches, “rights-framed” approaches as developed by Miller (2010) are discussed here. The final section briefly acknowledges alternative approaches to rights to define end of life, primarily a utilitarian approach, which has traditionally informed the basis for law and policy-making in the UK. Although a very different approach to that of rights, this perspective has implications in relation to selected arguments and documentation that are analysed in the following data chapters.

3.1 Foundational approaches

A foundational or essentialist approach to rights embraces the most common interpretation of human rights. Individuals are the bearers of human rights solely by virtue of their humanity. A foundational perspective, which encompasses natural law and liberal tradition, considers personal liberty, human dignity and, as more recently proposed by Turner (1993), vulnerability of the body, as foundations for the existence of rights. These concepts are examined below.

3.1.1 Natural law

A theoretical approach to human rights justified through natural law is centred upon the recognition of *pre-social* characteristics that define being human. These include “elements of the human condition that are essential to man’s nature and his full development as a human being” and are in some degree objective, accessible to reason, reflect human nature and enhance humanity (O’ Connor 1967, Whiting 1995). Natural law theory links these universal elements with moral principles that are bestowed without outside influence upon rational individuals and these often have a lawful character that inclines people to act or refrain from acting in a particular way (Zuckert 1996, Cranston 1973). Natural scholars²⁰ attribute human rights to being founded in nature but the majority recognise legal consensus and human rights law as a direct continuation of the human rights concept (Dembour 2010).

²⁰ A classification coined by Dembour in her 2010 paper “What are Human Rights? Four Schools of Thought”.

For natural scholars, the origins of human rights entitlements are found in nature, but the source of this nature is a topic for debate in the literature. A secular perspective grounds the source of the human condition in rational man as a freely thinking individual. In contrast, a divine perspective refers to man's nature as a creation of God, acknowledging the universal and God-given inclination of rational man that centres on the awareness of doing good and avoiding evil. John Locke, as a key proponent of natural law, designated the character of natural law as a duty owed to God (Locke [1689] 1970). Belief in the divine origins of natural law, and a God who is sovereign in matters of life and death, constitutes the foundation for religious opposition to the legalisation of assisted death. This view informs the contributions of some members in the House of Lords debates to be explored in Chapter 6.

Ishay (2008) argued that rights are historically derived from humanity and a spirit of "brotherly love". These views are echoed in ancient ethics and religious tradition and their origins can be found in Plato's and Socrates' conception of a universal "human goodness" (Ishay, 2008). Human nature has generally been argued as a foundation for a natural law perspective on human rights.²¹ Albers, Hoffman and Reinhardt (2014:1) highlight how "[h]uman nature as a concept is still widely used in contemporary philosophical and juridical discourse as a way of justifying the universal and egalitarian validity of the claim of human rights". Human nature, whether divine or secular in origin, is defended as the basis for human rights through both the moral status of individuals and a connection with human need²² and vulnerability. Another substantive basis for human rights within a natural law perspective is that of human value. Human value reflects the inherent worth and innate potential of every individual. Respect for these ideals underpins national and international human rights mechanisms, including as one example, the Universal Declaration on Human Rights, promoting "the dignity and worth of the human person" (UDHR, 1948).

Individual liberty

²¹ Grounding rights in human nature or human value necessitates belief that humans possess common attributes. However, human nature as a universal concept is contested by the constructionist argument noted by Freeman (2004:384) "[h]uman nature itself is partly a sociocultural product and consequently variable". This perspective is explored further in section 3.2.2.

²² On the basis of human need, goods that are indispensable for a reasonable life should be protected by human rights (Mieth 2014).

Liberalism as a political approach regards human rights as natural and liberal ideology reflects commitment to the values of freedom and equality of every person in society, believing that an individual's potential for rational action derives from their own reasoning and critical enquiry (Ishay, 2008, Heywood 2007, Jennings 1996). Key liberal philosophers John Locke and Immanuel Kant have formulated principles of liberty within different frameworks. Locke, as the founding father argued that all men are born free and equal. Human beings possess natural rights that are those values and moral norms deemed worthy of protection in a hypothetical "state of nature" independent of outside influence. Locke's contribution grounded the concept of autonomy in Western liberal theory and natural law tradition, but he also situated his idea of natural rights within a political context whereby the legitimacy of a government depended upon the respect that it accorded these rights (Locke [1689] 1970). The state of nature was, according to Locke, limited in practice by human beings that have a vested self-interest and a lack of monitoring by an independent judge who has power to enforce a common standard of law. As a preferable alternative that would enhance human flourishing, he suggested that men necessarily levy unrestricted liberty to ensure protection for themselves and their property and submit to rules drafted by the state to facilitate normative standards of conduct (Locke [1689 Bk II Ch IX] 1970:124).

Locke elaborated on the concept of liberty arguing that all human beings are entitled to certain rights derived from their own moral nature and considered one's individual property. His novel contribution argued this property to include one's own person,

Though the earth and all inferior creatures be common to all men, yet every man has a "property" in his own "person". This, nobody has any right to but himself (Locke [1689 Bk II Ch V] 1970:27).

This argument raises an important point relevant to the end of life debate and policy. Through the notion of the body as personal property, Locke emphasises that *individuals*, and only these individuals, have a right to decide over their own bodies and this conviction could be applied to the understanding of liberty rights to self-determine where and when life should end. The contemporary argument by philosopher Alan Gewirth also proposed that a right includes individual entitlement to exert control over one's own personal property,

[A] right is an individual's interest that ought to be respected and protected; and this "ought" involves, on the one side, that the interest in question is something that is due or owed to the subject or right-holder as her personal property, as what she is personally entitled to have and control for her own sake, and on the other side, that other persons, as respondents, have a mandatory duty at least not to infringe this property (Gewirth, 1996:9).

Locke traditionally argued from a divine perspective, but his sentiment expressed below indicated that there may be instances where man rather than God is sovereign over his own body. He suggested

But though this be a state of liberty, yet it is not a state of license; though man in that state have an uncontrollable liberty to dispose of his person or possessions, yet he has not liberty to destroy himself or so much as any creature in his possession but where some nobler use than its bare preservation calls for it (Locke [1689 Bk II Ch II] 1970:6).

Initially, Locke appears to disapprove of unrestricted liberty, and this is consistent with his philosophy that supports an active role of the state in curtailing liberty in certain circumstances. He claims liberty does not extend to man destroying himself or others. On closer inspection, this perspective could be drawn upon to justify unbearable suffering as a reason to warrant requested death. Locke builds a notion of rights upon individual liberty, and, on this basis, a claim could be made to conceive assisted death as a human right. Where suffering is burdensome and there is a protracted period of distress, it may be especially acceptable to want to end life prematurely. The ending of suffering is of “nobler use” than preserving life that is only endured for the sake of remaining alive.

At the heart of liberty is the right to determine one’s own concept of existence or non-existence. A Kantian perspective views individual self-governance as living by one’s own values and beliefs informed by a voluntary, rational choice. In contrast to Locke, Kant argues that the right of autonomy is not necessarily intrinsic to human beings, but is dependent on their “rational nature”. In this regard, autonomy is an exercise of evaluative choice, requiring rationality on the part of individuals to appreciate the extent of possible options and their consequences. At the end of life, in relation to assisted dying, the consequences of this decision are final and non-reversible. Review of the literature suggests that existential suffering and distress at the end of life can disrupt self-embodiment and this could undermine the principle of autonomy (Campbell, 1996). In addition, priorities and values can fluctuate or be subject to influence during the course of a long-term or life limiting illness and on this basis, one could argue there is a need to demonstrate a higher level of rational thinking and mental capacity in end of life decision-making.

From a contemporary perspective, Carel (2008:73) links the concept of individual liberty, articulated as personal choice, to human agency as a means to assert oneself and promote

one's own goals. For Lawton (2000:81), this sense of self involves the "ability to act as the agents of their embodied actions". A right to die could be conceived through a foundational approach to rights by emphasising the scope of personal liberty, not only in life but in death, and extending this to include the right to make end of life choices²³. A right to assisted death could also be a comforting possibility to the dying, knowing that if circumstances became unbearable, or suffering too great, then this option were available. In this way, respect for humans as thinking, intelligent beings in possession of reason and reflection is demonstrated. The right to self-determine end of life enables individuals to become "authors of their own self-transformation" (Spiers, 1997:29). Positions on liberty and dignity vary depending on the beliefs, priorities and purposes of different social actors and are analysed through the data as it emerges.

Human dignity

Dignity as a concept is generally associated with a natural law perspective on human rights. As one particular example, the contribution of political scientist, Jack Donnelly (2003, 2007), grounded rights in respect for the inherent dignity of human beings. He also argued that rights ought to be enjoyed "simply because one is a human being" (Donnelly, 2003:10). Recent literature, including Rosen (2012) and Kateb (2011), notes that dignity is often perceived as the basis for human rights. However, there is a lack of philosophical interest in dignity as a concept and a lack of scholarly discussion on what human dignity is or why it matters for rights. Rosen (2012: 31) proposes that human beings are accorded dignity by virtue of the humanity in their persons, which may be due to an inherent sense of morality within us all that presumes individuals intrinsically valuable. Kateb (2011:10) links the notion of identity towards theorising innate dignity within a human rights discourse. He argues that the

...idea of human dignity insists on recognising the proper identity of the individual or species, recognising what a person is in relation to all other persons and what the species is in relation to all other species.

Immanuel Kant, as a key Western philosopher associated the concept of dignity with an innate human worth. In his *Metaphysics of Morals* he noted the inherent nature of dignity claiming "he possesses dignity (an absolute inner worth) by which he exacts respect for himself from all

²³ It is important to note here that decisional autonomy in an end of life context could also involve the option of choosing not to avail oneself of a right to die. The knowledge that assistance to die was available, and deciding not to request this course of action, could be empowering for a dying person who makes a conscious decision to continue to live.

other beings in the world” (Kant [1797] 1990:434). For Kant, dignity has an unconditional value. In contrast to a divine perspective, he associated dignity as the basis for morality from a secular position that may better resonate with contemporary and humanist perceptions of dignity and rights. Conceptions of rights, dignity, respect and duty are central to Kant’s morality and underpin his condemnation of suicide. Kant’s position on suicide, presented in his lectures on ethics, is well-known. He states

To preserve his person he has the right of disposal over his body. But in taking his life he does not preserve his person; he disposes of his person and not of its attendant circumstances; he robs himself of his person. This is contrary to the highest duty we have towards ourselves, for it annuls the condition of all other duties; it goes beyond the urn of its use of free will... (Kant [1775-80] 1963:147-154).

This position argues that suicide violates the “highest duty” including concepts of duty to others and duties that rational beings owe to themselves, individuals being morally obliged to protect their lives based on their inner and alienable dignity. For Kant, the notion of duty is of primary importance. He elaborates on the performance of duties in relation to personal freedoms,

Those who advocate suicide seek to give the widest interpretation to freedom. There is something flattering in the thought that we can take our own life if we are so minded; and so we find even right-thinking persons defining suicide in this respect. There are many circumstances under which life ought to be sacrificed. If I cannot preserve my life except by violating my duties towards myself, I am bound to sacrifice my life rather than violate these duties. But suicide is in no circumstances permissible (Kant [1775-80] 1963:147-154).

Kant differentiates between the self-inflicted actions of suicide and sacrifice. Suicide is not deemed permissible in any circumstances. The violation of duties towards oneself and potential duties that are unable to be performed for the benefit of others when one’s own life is ended are too great. In contrast, Kant defends self-sacrifice on the basis of duty to oneself suggesting there are “many circumstances” under which this “ought” to take place, although he does not elaborate further.

The concept of dignity did not inform the language of law and jurisprudence pre 20th century. There is no legal right to dignity *per se*, but it has increasingly featured in international legal documents since the UDHR 1948 (Schroeder, 2012:323). A foundational understanding of human dignity and rights is linked in the UDHR Preamble, which states

Whereas recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family is the foundation of freedom, justice and peace in the world (UDHR 1948).

The inalienable nature of dignity is challenged by the fact that personal dignity may be lost or destroyed. This resonates with a social constructionist position (explored in section 3.2.2) that argues dignity is given content by a range of political, social and religious convictions (Rosen, 2012:7). Even accepting that all human beings have an inner or unconditional dignity or value, the meaning of dignity will vary according to individual perspective and experience. Rosen (2012:46) argued that modern conceptions of human dignity include an "amalgam of humanist, liberal, Christian, socialist and Kantian ideas". Jacobsen (2007) attempted to reconcile a foundational and constructionist approach to dignity. She suggested categorisation into "human" and "social" dignity. Human dignity reflects an inherent, inalienable value by virtue of being human and social dignity as a contingent consequence of recognising human dignity in others which may then be bestowed, earned or diminished through interaction in a social setting (Jacobsen, 2007).

Human dignity could offer a credible basis for the existence of human rights. Through the generally desirable notion of a dignified death, an understanding of dignity grounded in rights could offer a plausible basis for a right to die. However, the definition and phenomenology of dignity is ambiguous. It remains open to theorisation and interpretation by social actors and is criticised as a "vacuous concept" because it lacks legal and philosophical boundaries and cannot explain narrower interests. Bagaric and Allan (2006:263) argued,

For dignity to provide meaningful guidance to judges and lawmakers...regarding the scope, acceptance and development of concrete rights, a number of matters need to be resolved including the meaning and justification of dignity.

Dignity as a concept grounded in human rights was identified through the literature as an interesting and relevant area to study in relation to the end of life. Dignity and the associated vocabulary of "choice", "rights" and "respect" feature prominently in UK healthcare and end of life policies to be examined in Chapter 5. Maintaining human dignity is prioritised throughout healthcare policy and practice. Individuals working within health and social care or benefitting from the attentions of professionals working within these areas especially relate to the concept of dignity (Jacobsen, 2009). The complexity of the assisted dying debate is highlighted here; understandings of human dignity normally relate to dignity in life rather than death. Respect for human dignity that encompasses *dignity in dying* is used as an argument by some social actors who suggest a right to die can enhance human dignity through the avoidance of

an undignified death. The concept of dignity in dying is critical to this research and will be discussed through analysis of the data.

Vulnerability of the body

Alongside concepts of liberty and dignity that underpin a foundational position on human rights, a novel approach was proposed by Bryan Turner through a sociological understanding grounded in the vulnerability of the body (Turner, 1993). His contribution outlined a theory of human rights through a foundational ontology of rights based upon human frailty as a universal feature of human existence. This “Frailty Theory of Human Rights” centred upon the idea that

Human beings are frail, because their lives are finite, because they typically exist under conditions of scarcity, disease and danger and because they are constrained by the physical processes of ageing and decay (Turner, 1993:501).

Turner argued that humans are frail. We are all mortal and constrained by ageing and illness that reduces our physical/mental ability and participation in social life. Especially in the dying process, the vulnerability of human beings is a convincing argument upon which rights could be validated. At the end of life, human beings are alone with their pain, confronted by their finite existence. Human vulnerability in the face of inevitable death *is* universal, irrespective of the historical, social or cultural context in which they exist. Despite scholars who contest this position,²⁴ human frailty is evident in the experience and process of dying.

Turner’s theory does however acknowledge the disparity over the universal characterisation of human frailty, the above quote continues,

²⁴ In reply to Turner’s foundational ontology of human rights, Malcolm Waters contests an ontological grounding of human rights on the basis of frailty alone and argues that a sociological approach to rights is necessarily constructionist (Waters, 1996). Waters argues that the concept of human rights is itself an institution that reflects prevailing interests and thus by its nature is historically and culturally specific. He states

...human rights is an institution that is specific to cultural and historical context just like any other and its very universality is itself a human construction. The construction of human rights demonstrably transpires in the field of politics and its institutionalization is an emergent arrangement that reflects prevailing balances of political interests. Such a view is, one must insist, positivistic rather than foundationalist because it relies on locating the emergence of human rights within historical configurations of interest (Waters, 1996:594).

Turner (1997: 566) later replies to Waters, suggesting that a sociology of rights can have a foundational ontology that centres upon human frailty, whilst also accepting that human rights are relative to historical and cultural contexts, and determined by political interests.

Against this characterisation of human ontology it can be argued that this condition of frailty is historically and culturally variable and that therefore it cannot function theoretically as a substitute for natural law (Turner, 1993:501).

The literature in section 2.1 noted advances in modern medicine and technology that can prolong life and alleviate symptoms of suffering, perhaps disputing individuals as frail. Turner contends that technology and social modernity have changed the circumstances of human ontology, but not necessarily for the better. He implies that modern life is now subject to a range of diverse threats and challenges. These threats arise from the “precariousness of social institutions”. Furthermore, he claims the very institutions that are designed to protect human beings such as the state, law and church may abuse their power (Turner, 1993:502). Turner elaborates upon the vulnerability of the body as an entity that is subject to protection or exploitation by institutionalised rights and he insinuates that the human body is in a “dynamic relationship” with this precariousness of social institutions (Turner, 1993). These points are considered together with other contributions under a social constructionist approach in section 3.2.2.

The notion of collective sympathy provides a platform for a subsequent and vital step in Turner’s argument that sympathy emerges as a consequence of, or a supplement to, his theory of human frailty (Turner, 1993:506). Collective sympathy arising from human frailty implicitly locates human rights within a common social act of recognition such that “the idea of frailty requires the support of a theory of sympathy to underpin the sociological nature of this argument about the connection between frailty and human rights” (Turner, 1993:506). The notion of collective sympathy arises historically from interpretations of the Golden Rule of Reciprocity that constitutes a fundamental human principle echoed in many religious doctrines. This is clearly defined in the Christian Bible as the command “do to others as you would have them do to you” (New International Version Bible, Luke ch6 v31). Turner develops this notion as being responsible for the formation of moral communities and claims this may propagate the institutionalisation of particular rights on the basis that “[h]uman beings will want their rights to be recognised because they see in the plight of others their own (possible) misery” (Turner, 1993:489). Turner’s contribution is meaningful because it suggests a cross-cultural ontological foundation for claims to rights. It also explains how support for rights is generated through evoking a common human sympathy reflecting compassionate man.²⁵

²⁵Compassion as a concept is not generally grounded in a human rights approach. Turner’s theory broaches the idea that the capacity for compassion is part of a human identity and respect for human rights may be dependent upon shared compassion for our fellow beings.

Turner's frailty theory of rights grounded in human vulnerability is an important tool for analysing the right to die. Particularly in the case of dying individuals, it can provide an ontological basis to explain why human beings have rights during, and at the end of, life and how these should be conceptualised and discussed. Human beings are vulnerable physically and mentally when facing an incurable or serious illness and in the dying process. This is recognised to an extent in the UK and available options at end of life are regulated by the legal system, the institutionalised medical model and current healthcare practice.

3.2 Anti-foundational approaches

An anti-foundational perspective views human rights as constructed and relative to a specific social context. This approach involves understanding rights without metaphysical grounding either on the basis of natural law relating to God, as in the tradition of Locke, or on the basis of reason and logic, as proposed by Kant. Human rights are neither inherent nor innate according to an anti-foundational perspective, but rather time and context dependent. This position can be useful to explain socio-cultural variation in the nature of human rights claims and the foundations of the human rights institutions designed to protect them. This section is divided into two parts. The first explores legal positivism as one basis for understanding legal rights. The second explores a social constructionist approach that grounds and analyses claims to rights through an emphasis on the social, rather than the legal context.

3.2.1. Legal positivism

A legal positivist position on rights assumes human rights and subsequent claims to rights as solely designated and legitimised through the action of a nation state enshrining and protecting them in law. Legal positivism, as an approach to rights, looks to the recommendations of the political and legal systems for guidance on permissible conduct in relation to complex social dilemmas. On this basis, UK law and policy has an important role in determining end of life issues. Analysis of the relationship between law and morals is not the priority for this thesis (see for example, Hart et al, 1958), but the law does have a normative function. Statutory and policy provision will define the options available at the end of life and shape how the public thinks about these options. UK law and politics has a traditional understanding of rights as legal entitlements. Individuals are part of civil state linked inextricably to institutions that customise standards of behaviour and this, according to Vincent, (2010:5) illustrates the "intrinsically political" nature of human rights. The role of the

nation state is critical to a legal positivist understanding of rights. The responsibilities of a liberal, democratic government, as law and policy makers, include defining and protecting human rights with regard for the safety and well-being of its citizens. Liberal political philosophy acknowledges individual human rights as interests of the state and recognises that the state has a duty to maintain personal security and limit harm to all its citizens.²⁶

From a legal positivist perspective, realisation of a right to die would potentially involve amendment of statutory law, legislation of a new right or extending the boundaries of and appropriating existing rights in a new area. As a result of this the status of the dying person meeting the eligibility criteria²⁷ would be classified as a “rights-holder”. Feinberg (1980:151) suggests that to think of oneself as a rights-holder is empowering, it involves elements of pride and self-esteem, being worthy of respect from others. Classifying the dying person as a rights-holder positions the state and other actors, potentially including members of the community as duty-bearers who can be held responsible for discharging legal obligations or duties. For most human rights theorists, duties are not considered a precondition to human rights, but rights do often involve duties both to fulfil moral or social obligations and to respect the rights of others (Etzioni and Brodbeck 2012, Freeman 2011, Douzinas 2000 and Bobbio 1996). If dying individuals were granted a right to request assistance to die, the state would become responsible for discharging legal obligations that would include nominating a duty-bearer to assist a suicide in order to enable the right of the rights-holder to be fulfilled. There is some debate over the extent to which rights and duties are correlative, which prompts the question of whether concepts of rights can exist without a duty-bearer. O’Neill (1996:129) asserts that any principles defining a right also entail a duty or obligation that is assigned to others in order that rights-holders may claim or decide to waive the right, or can pursue a remedy for breach of this right. She suggests that if these duty-bearers are unidentified, then the right cannot be claimed, waived or enforced (O’Neill, 1996:129). In light of continuing opposition from the medical professional bodies, and lack of suitable, alternative proposals, there is currently no agreed consensus upon whom has an obligation to act as a duty-bearer and it is undetermined where, or with whom, the claim would be lodged.

²⁶ This has traditionally raised an important question particularly within sociology on the nature and origins of citizenship as a concept (see Marshall 1950, Turner 1990, 1993). The pragmatic argument initially conceived by Arendt (1958) noted that human rights are only meaningful if the state recognizes its inhabitants as citizens and, thereby, bearers of human rights. She questioned whether individuals who are not recognised as citizens, that is, members of a nation state and are in effect stateless, are they also entitled to rights and protection by the state? (Arendt, 1958).

²⁷ Current proposals debated in the House of Lords specify eligibility/ safeguarding criteria as age, terminal illness and rational capacity as requirements, and therefore the right to die would not be equally or universally available to all.

Respect for the rights and freedoms of others is a key issue in the end of life debate which involves state responsibility to balance the rights of individuals against protecting the rights of the rest of society. On the extent of personal freedoms, the UDHR 1948, Art 29 suggests that individual liberty shall only be limited by the nation state in particular circumstances. These include; “securing due recognition and respect for the rights and freedoms of others and meeting the just requirements of morality, public order and the general welfare” (UDHR, 1948). One of the main arguments against the legalisation of assisted death is the potential for abuse. Opponents claim that by initially permitting an assisted death for individuals meeting the criteria, the parameters for requested death may later shift. If the proposed safeguards broaden, there is a concern that mentally incompetent, vulnerable or frail elderly adults may be subjected to an assisted death without request. This slippery slope²⁸ may result in non-voluntary euthanasia of disadvantaged individuals and change the ways in which society regards the ending of life.

A common critique of rights is highlighted here. Through their egocentric nature, rights focus on the individual as a basic moral unit serving to recognise and protect individual claims at the expense of consideration for the wider community (Campbell, 2006). Contesting this critique, Kateb (2012:67) argues that even if rights originate from egocentric self-interest, the recognition of a certain right may validate a claim that can potentially benefit all. In practice, an initial consideration is expanded upon to improve conditions for others. A legalised right to die could potentially benefit the whole community by extending choice at the end of life to some individuals, who for their own reasons, may desire an assisted death. Although a right to

²⁸ Academic research by Battin et al as recently as 2007, disputes evidence of a slippery slope or any disproportionate impact of legalising assisted suicide. This study based on data from Oregon and the Netherlands uses subjects from 10 groups of potentially vulnerable patients. Data collected from Oregon included all annual and cumulative Department of Human Services reports in the period 1998–2006 plus three independent studies. Data from the Netherlands comprised all four government-commissioned nationwide studies of end-of-life decision making in 1990, 1995, 2001 and 2005 plus specialized studies. Analysis of the data indicated the rate of assisted dying in Oregon and in the Netherlands showed no evidence of heightened risk for the following groups: elderly, women, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses including depression, or racial or ethnic minorities, compared with background populations. The sole group with a heightened risk was people diagnosed with AIDS (Battin et al, 2007). This research concluded that where assisted dying is already legal, there is no evidence currently indicating that legalized physician assisted suicide or euthanasia will have disproportionate impact on patients in vulnerable groups, and more notably those who did receive physician-assisted dying in the jurisdictions studied appeared to enjoy comparative social, economic, educational, professional and other privileges.

die would only be accessible to individuals meeting the safeguarding criteria, legal recognition could bring end of life issues more into focus as a topic for discussion and collectively identify the dying as a vulnerable group in need of further resources to protect their rights.

Some rights-adherents do seek to institutionalise their claims, and normative principles of human rights may motivate actors towards legal entrenchment. On occasion, the fulfilment of one right may infringe upon the rights of other members of society or adversely affect or conflict with another already established right that highlights the difficulty in defining normative understandings of human rights principles (Freeman, 2011:6). Legal recognition of a right to die would directly conflict with, and challenge, an already established right to life (a non-derogable right protected under national and international human rights mechanisms that the UK has ratified). Kateb (2012:31) suggests “[t]endentious interpretation makes rights conflict”. Human rights are sometimes conflicting or contradictory in nature. Their boundaries are open to interpretation by actors and circumstances that may either further develop and extend existing rights or impede their recognition or legal implementation. This idea is demonstrated in the research through the legal appeals of Diane Pretty and Tony Nicklinson.

The democratic process may increase the legitimacy of a right, but a legal positivist approach to human rights is criticised in the literature as inadequate to analyse the ethical, political, social and economic dimensions of human rights or measure validity or accountability (Wilson 2007, Freeman 2002, Etzioni 1997). With issues as complex and personal as the dying process, the formal status of law may be rejected, as illustrated by the following comment

law binds in conscience, yet this is because it is the law only if just and promulgated by legitimate authority, not because the majority or the law can be a standard of conscience...the law has an educational function and tends to develop moral virtues...[but] the state has not the authority to make me reform the judgement of my conscience any more than it has the power of imposing upon intellects its own judgement of good and evil (Maritain, 1971:77).

This disregard for the law in preference for individual standards of conscience, often motivated by distressing personal circumstances and including unbearable suffering, could explain why assisted suicide, although illegal, does occur in a number of UK cases. These cases are routinely investigated by the police and yet, most are not prosecuted. This conundrum is discussed further in regard to analysis of current law and policy and arises as a topic for debate in focus group discussion.

3.2.2 Social constructionism

In contrast to legal and foundational perspectives, a social constructionist theory of rights emphasises that rights are a product of their social environment. Bryman (2008:19) explains how a constructionist ontology implies that social phenomena are produced through social interaction and are in a constant state of revision. This perspective encourages investigation of how particular meaning is ascribed to the act of assisted death and the activities of social actors that are driving this. A social constructionist perspective can provide a way of understanding human rights and enables a focus on the role of social actors and their use of rights discourses. This could help explain how a notion of rights at the end of life, including a right to die, could arise and become embedded in a contemporary UK context.

One powerful way in which attitudes towards death and dying are shaped is through discourse. A discursive approach to rights is part of a social constructionist position that regards rights as a linguistic expression, adopted by different actors, who, in a specific time and context, consider a rights frame to serve their purpose. Goodale, (2007:7) argued this approach to human rights, as discourse, is interesting because the “study of human rights as discourse reveals the way in which actors embrace the idea of human rights, in part because of its visionary capacity, the way it expresses both the normative and the aspirational”. Certain distinctions and individualised meanings are both evident and constructed through language. Merry, (2006) suggested the adoption and understanding of rights discourses varies according to the purposes of social actors,

Whether local actors develop a human rights approach depends on their perceptions of its success. Human rights discourse may be rejected by local actors; it may merely decorate local practices; it may combine with local discourses in a hybrid; or it may subvert and displace prior discourses (Merry, 2006 cited in Freeman, 2011:110).

Merry’s (2006) observation that a rights discourse “may subvert and displace prior discourses” may be useful to analyse the data from the House of Lords debates and the case study on Dignity in Dying.

Critical theorists develop a social constructionist paradigm further through the basic assumption that all thoughts are socially and historically constructed, but, in addition, they are fundamentally mediated by power relations and the role of language that is central to the formation of subjectivity (Kincheloe and McLaren 2002). Power relations, discourse and the construction of knowledge are particularly relevant to the debate on assisted death. Malcolm

Waters (1996:595) writing from a social constructionist position argued that rights become recognised and institutionalised when social actors exert pressure on political authorities who then perceive that the institutionalisation of rights would be as much to their advantage as it is to those pursuing a claim. He claimed that the “institutionalization of rights is a product of the balance of power between political interests” (Waters, 1996:595). Power relations and institutional practices in contemporary society are influenced by a range of social actors and organisations who, through their activities (and campaigns), can raise awareness of an issue, mobilise public support and bring forward the issue on the political agenda by utilising particular discourses that resonate with target audiences.

In contemporary society, rights discourses are becoming increasingly salient to the extent that they could inflate and sustain a challenge to medical practice and political institutions that determine permissible frameworks for end of life. Social actors use techniques that include framing and foregrounding of texts and relate this to prior knowledge and societal attitudes as a strategic method to challenge the prevailing status and impact social practice (Paltridge, 2006: 185). Human rights discourses have, in regard to specific issues,²⁹ been instrumental in extending the scope and boundaries of existing rights and gaining protection for these both in national and international mechanisms. Framing human rights as *claims to* something, for example, a *right to die* does appear to increase their validity and they become less politically negotiable so that framing processes are a central dynamic in understanding the character and course of social movements alongside resource mobilisation and political opportunity (Benford and Snow, 2000: 611). Framing techniques can function as a powerful means of accessing social advantage without always having to provide a “matching contributory performance” and this may explain why there is an increase in the prevalence of social issues being expressed through human rights discourses (Waters, 1996:595).

A significant contribution was made by Miller (2010) who used a broad social constructionist conception of rights to analyse what had commonly been referred to as “rights-based approaches”. Miller’s (2010) analysis in the context of non-governmental organisations (NGO’s) campaigning for development goals, took issue with the overarching concept of rights-based approaches. Rights-based approaches traditionally use rights to define the ideological base of the organisation. Strategic priorities are grounded in international human rights

²⁹ Anti-discrimination rights that now afford protection on the grounds of disability and sexuality, and provision for women’s rights, which encompass a right to choose in the case of permitted abortion are suggested as contemporary examples.

standards or refer to these. The NGO campaign goals are commonly motivated by the power of the idea of universal human rights. Miller's (2010:915) critique argued that rights-based approaches (hereinafter RBA) can be "expansive in their reach and diverse in practice". Instead, she proposed "rights-framed approaches" as a framework incorporated by certain NGO's (Miller, 2010). In contrast, rights-framed approaches tend to make less reference to international human rights mechanisms. "Rights talk" is incorporated strategically through a human rights frame, and usually only at an operational level. Rights-framed approaches (hereinafter RFA), are driven by ideological underpinning and rights discourses are frequently adopted as a campaign tool that utilises this frame to interpret and transform an issue (Miller, 2010:923). In this way

Rights-framed approaches do not start from nor are defined by a normative understanding of human rights frameworks...but instead they are defined by the ideological foundation of the NGO (Miller, 2010:925).

This approach is used as a way to serve the ideology of the organisation by repackaging ideas and beliefs for the purpose of promoting and advancing the campaign objectives so that RFA's are used as a "tool to serve the NGO's official approach" (Miller, 2010:925). There are choices to be made in regards to how rights talk should be incorporated and this inevitably means that there will be a variety of voices within the organisation that will interpret the strategic value of rights talk in different ways (Miller, 2010:260).

Miller (2010) proposed a RFA in regard to development and argued that campaigning organisations often adopt human rights frames for tactical purposes. These purposes, consistent with wider trends within existing social movement theory, suggest that RFA's have the potential to: 1) motivate and mobilise collective actions; 2) legitimate action; 3) advance own beliefs and aspirations; 4) demobilize antagonists; 5) transform the terms and nature of the debate, and 6) fit with favourable institutional venues (Miller, 2010). Rights-framed approaches are proposed on six key dimensions and these contribute a new framework, revealing the ways in which campaigns can be framed through human rights discourse and practice, whilst remaining "outside" of RBAs (Miller, 2010:1). This framework may also be applicable in a different context, more specifically, to develop the case study analysis of the campaign for Dignity in Dying in a new and, as yet unexplored, area. Assessing the incorporation of a RFA as a strategy employed by an organisation that campaigns for legal change on assisted death, would be a response to Miller's call to take advantage of her research findings and advance these through further case studies. The table below presents

Miller's 2010 research findings that contrast rights-based and rights-framed approaches. This systematic format has been adapted and reproduced with her permission.

Figure 3.1 Contrasting rights-based and rights-framed approaches in development campaigning

(Miller, 2010:924)

<i>Rights-based approaches</i>	<i>Rights-framed approaches</i>
The official approach	Used as a tool to serve the official approach
Drives NGO policy	Is driven by NGO policy
Starts from and makes reference to human rights	Starts from ideological base, then strategically repackages beliefs and ideas through a human rights frame to potentially: motivate/mobilise collective action, demobilise antagonists, legitimate action, advance own beliefs, transform terms of the debate and 'fit' institutional venues
Commonly motivated by the power/ idea of universal human rights and will use this to motivate others (activists and campaign targets)	Will strategically utilise the power of the idea of universal human rights to motivate others (activists and campaign targets)
Strategic priorities are either based on	Strategic priorities may make references to

and defined by international standards, or make reference to these through the language of rights	ideas of human rights but this is not required
Frequently appeals to rights across all campaign contexts	Only appeals to ideas of rights when considered to be strategically advantageous to specific campaign contexts
Frequently cites specific human rights language, covenants or agreements	Only on occasion and when beneficial will cite specific human rights language, covenants or agreements
Concept of universal human rights is used as the basis for legitimacy in most contexts	Concept of universal human rights is used as the basis for legitimacy in precise contexts when strategically advantageous

3.3 Alternative Approaches

This chapter has examined different positions on rights including foundational and anti-foundational perspectives to suggest how a right to die could be envisaged. It is critical at this point to acknowledge that what was commonly termed as rights-based theories are not the only means through which the end of life debate and policy on assisted death may be approached. As an alternative, there are goal or duty-based theories³⁰ that do not necessarily involve rights and are generally propagated by a desire to further whole community interests (Freeman, 2014: 501). Utilitarianism is one goal-based method of distributing social justice. It is the traditional basis for law and policy making in the UK, and for this reason, is considered here. Utilitarianism, as a school of liberal thought, presents a contrast to theories of rights and

³⁰ Examples include a Rawlsian theory of political justice that promotes justice as fairness and very broadly rests on ideals of maximum personal liberty, equality, and elimination of inequalities of opportunity based on birth or wealth (Rawls, 1971:13). Another goal-based theory of social justice is based on human needs that include physical/ mental health, personal security, understanding and social relations, and these basic human needs are important enough to generate moral obligations requiring protection by the nation state (Mieth 2014, Brock 2005, 2009). Human capability has also been argued as a theory for social justice. Core capabilities include bodily health, integrity, reason including critical reflection on planning life and control over one's environment and these should be respected by government as a requirement for human dignity (Nussbaum and Sen, 1993).

as the research findings emerge, the principle of utility may be revealed as important to some social actors in their approach and attitude to the end of life debate and policy.

A utilitarian approach rejects rights in general. Bentham's historical critique dismissed natural rights as "nonsense upon stilts" and claimed that "[a] right without a law is an effect without a cause" (cited in Belden Fields, 2003:28). The limited utilitarian understanding of rights is "the beneficiary of a duty...one benefits from another's performance of an action required of her" (Bentham cited in Waldron, 1987: 35). The utilitarian perspective developed by Bentham and Mill states that human beings acting as free and rational creatures will naturally pursue their own interests, thereby creating a social order that results in "the greatest good for the greatest number" (Sjoberg et al, 2001: 15). This approach assumes government responsibility to provide a normative framework to facilitate optimal circumstances for all citizens to achieve happiness. However, measuring individual interpretations of happiness is particularly subjective. Bentham's theory of utilitarianism is concerned with institutionalising the happiness principle to enable the law to determine optimum social policy. He proposes this is determined by balancing the amount of pleasure or pain one may suffer in any action against any future or resulting pleasure or pain, and that this criterion is the only rational foundation for law and utility (Bentham, cited in Waldron, 1987: 30).

A utilitarian framework based on the happiness principle, arising from the concepts of pain and pleasure, is inadequate when making end of life decisions. It is impossible to predict a future degree of unhappiness or pain an individual will experience in conjunction with a terminal, progressive or debilitating illness or make generalised value judgements about how individuals should, could or would cope with this. Kateb (2011:86) argued that the pain versus pleasure notion is flawed because pain can result in serious infringement upon human dignity whereas pleasure only brings incremental material advantages. In addition, a utilitarian perspective can be criticised for neglecting individual freedoms, promoting instead the common purposes of society and revolving around majority preferences to arrive at legally binding decisions. On a utilitarian basis, one could argue that current laws prohibiting assisted suicide prevent abuse, and are therefore beneficial to the wider good and protection of society as a whole. Opponents of assisted death often adopt a utilitarian argument to challenge legalisation of a right to die amid fears that it could threaten the well-being of the vulnerable and elderly in wider society. However, this approach ignores heartfelt, rational requests for assistance to die in the face of unbearable suffering. One could consider current legislation, and end of life

practice, to be lacking compassion in balancing the intolerable pain of dying individuals who request help to die against the common good. This in itself poses a dilemma with regard to the balancing of harms. How do legislators decide whose interest to protect when a right to die could upset those affected by the death of the individual, with potential repercussions in wider society, but where prohibition causes harm to those who are suffering unbearably and request assistance to die?

Conclusion

Different frameworks of human rights have been explored in this chapter to illuminate the ways in which rights may be understood and given meaning by social actors in an end of life context and how, as a result of this, a right to die might be conceived. Three main positions on rights were examined and these may be recognised in the subsequent research data. A foundational approach was defined initially. This was useful to ground concepts of individual liberty and human dignity from a historical and philosophical perspective. Freedom to determine the manner and timing of one's own death is supported by a foundational approach to rights that emphasises personal liberty and dignity in the dying process and underpins a right to die on the basis of man as a rational, freely choosing individual. Turner's (1993) contemporary "Frailty theory of human rights" grounds a foundational ontology of the body in a human vulnerability. This proposal is particularly poignant in relation to the end of life. Dying individuals are frail, they are at the mercy of death as an unknown entity and the precariousness of social institutions that provide and dictate standards of care at the end of life. From a foundational perspective, human rights discourses are characterised by understanding concepts of individual liberty, human dignity and vulnerability as inalienable and inherent. However, the selected vocabulary, that is used to interpret and articulate liberty and dignity, may vary depending on the different social actors. For example, notions of choice or control may be expressed, or the relief of suffering highlighted, in order to achieve a dignified death. The main limitations with this approach are the prioritising of individual liberty rights over respect for the welfare and values of the wider community and the advancement of a constructionist conception of human rights that disputes a notion of their pre-social grounding, instead emphasising the necessity of analysing rights in a social context.

Anti-foundational approaches to human rights that include legal positivism and social constructionism argue that rights are a product of their environment and subject to social, political, legal and cultural influences. Legal positivism argues that claims articulated as rights

are realised and legitimised through the action of a nation state enshrining and protecting them in law. Rights arise as a product of political and legal institutions that customise normative standards of behaviour and guide social conduct. Within this framework, it is the responsibility of the nation state to protect the rights or entitlements of citizens and, where indicated, this includes nominating a duty-bearer to enable the rights of a rights holder to be fulfilled. Democratic processes may increase the legitimacy of a right and there are a number of actors who adopt this position. However, a legal positivist approach may be inadequate to analyse the ethical, political, social and economic dimensions of human rights issues that are as complex and personal as dying.

A social constructionist approach that analyses human rights in a social context can help explain how new human rights claims arise and become embedded in practice. Human rights discourses can be used selectively and interchangeably so that new claims, articulated as rights, can be applied to a range of domains, in this case, at the end of life. A number of social actors and organisations have incorporated rights discourses to appropriate and proliferate new sets of rights claims and to successfully facilitate institutional change. This could, in future, potentially include right to die organisations. In the context of development NGO's, the work of Miller (2010) has advanced an understanding of the strategies that may be employed in a campaign context outside of traditionally labelled rights-based approaches. This forms the basis for analysing the 2014 campaign for Dignity in Dying in Chapter 7. Social constructionism provides a framework to enable a focus on how rights discourses are adopted by different actors. This approach was taken up in order to analyse the research data as it emerged. The following chapter describes in detail the research methods used to study the centrality of human rights discourses in relation to UK end of life policy and debate on assisted death.

CHAPTER 4

Research methodology

The purpose of this chapter is to explain in detail the research methods undertaken to test the hypothesis that rights discourses have become salient in an end of life context. Each part of the research design examined how, when, for what purposes, and to what extent, selected social actors used human rights discourses across written and spoken texts. This chapter is divided into three sections. The first section clarifies the approach to conducting the research and refreshes the research objectives. The second section examines the research design including the rationale for selection, the process of data collection and analysis, and critical reflection of the chosen method. Due to the sensitive nature of the research and contact with human subjects, especially in focus group discussions, there were ethical implications. These are considered in the third and final section.

4.1 Conducting the research

A broad social constructionist approach using a qualitative strategy was employed throughout this research. In comparison to quantitative approaches, qualitative interaction with research

subjects can explain in more depth how human rights issues are understood, and their meanings interpreted. A number of social science researchers argue qualitative analysis can identify underlying social values and processes, and more thoroughly illuminate the perception of a situation at a given point in time (Tonkiss 2008, Dickson- Swift et al 2008, Seale 2004, Denzin and Lincoln 1998). Discourse analysis is one way of questioning the basic assumptions of qualitative research. This was selected as a method to study how issues at the end of life were being expressed in the public and political domain, and to reveal what different actors understood by having a right to die. Discourse analysis can reveal how social actors, institutions and policy are implicated in constructing and sustaining a “system of beliefs” through their use of language strategies which reflect, and can influence, social, political and cultural practice (Hastings, 1998:193).

Rapley (2007:128) suggests that “[f]or those analysing discourse, the primary interest is *how language is used in certain contexts*”. This research examined patterns of human rights language across written and spoken texts, in relation to end of life. Closer examination of this language and the actors using it could provide an explanation of how and to what extent particular discourses are becoming central to UK end of life policy and the debate on assisted death. Discourses used to define death and dying are especially important because they are interpreted and understood by individuals who will, at the end of their lives, be confronted by an irremediable, unfamiliar and sometimes desperate situation. The dying are identified through the literature as frail. Death is an unknown entity and individuals who are vulnerable at the end of their lives could be influenced by the ways in which death and dying are spoken about, especially when compounded by the experience of pain and suffering. The original contribution made towards understanding this multi-faceted debate on assisted death is examining the centrality of human rights discourses with regard to *who* is using it and asking *how* it is used. What do different actors mean when, and with what intentions do they articulate options at the end of life as a “right to die”?

In order to answer the overarching research question, “[a] right to die? Examining the centrality of human rights discourses to end of life policy and debate in the UK”, the objectives defined in the introductory chapter are refreshed before the research process undertaken to meet these objectives is discussed. These include to:

- *examine evidence of rights discourses in UK law and policy;*

- *explore the prevalence of rights discourses in the historical and contemporary debates on assisted dying;*
- *analyse how and why an organisation which campaigns to legalise assisted death use rights discourses;*
- *assess the extent to which public perceptions on death and dying invoke rights discourses.*

4.2 Research design

The research design included analysis of a range of both current and historical texts, for example, texts produced by powerful or influential actors, texts interpreted by a large number of recipients, and spoken language to hear the public voice (Philips and Hardy, 2002:75). This section sets out, in-depth, the stages of the research design in chronological order of the research process to meet the four objectives stated above.

4.2.1 Examine evidence of rights discourses in UK law and policy

Rationale for selection

Document research accessing primary data sources to analyse official UK³¹ law and policy was selected to provide a clear picture of current end of life provision and investigate where regulations and standards in these mechanisms are being grounded in, or articulated through, human rights discourses. Law and policy play a critical role in the determining of attitudes and behaviours on end of life. However, analysis of the impact of these was largely absent in the literature.

At the outset of this research in 2012, and continuing into 2013, document analysis was prioritised to clarify what is, and is not permitted in law and to evaluate aspects of law and policy that refers to assisted death or assisted suicide. Analysis of UK law and policy illustrated

³¹ Characteristics of the Scots law and Northern Ireland legislation are similar to those in England and Wales, but there are variations between the jurisdictions. Chapter 5 clarifies where law and policy are specific to England and Wales.

the language used to define end of life care and available options for dying individuals, their families and carers. During the period of data collection 2012-13, end of life provision in UK statutory law included the Suicide Act 1961 and Homicide Act 1957, and these remain un-amended to date. Relevant healthcare policies at the time of study included the NHS Constitution 2013, and Department of Health End of Life Care Strategy 2008³². These were selected for analysis. Examination of both statutory law and policy revealed areas that were defined through rights discourses or respect for human rights principles. It also exposed areas in policy that challenged aspects of the current legal status of assisted dying as inadequate or with scope for amendment.

Legal petitions by seriously or progressively ill individuals who request assistance to die have been covered extensively and brought to my attention by the UK media and, on this basis, two cases were selected to assess their contribution to developing the notion of a “right to die”. Analysing the legal petitions and resulting judgements in the cases of high profile individuals, termed “right to die celebrities” by Richards (2014), demonstrates how rights discourses are being appropriated in a new context and used to challenge the scope and nature of existing rights. The legal appeals of Diane Pretty in 2001 and Tony Nicklinson in 2012 to the Court of Appeal and the Supreme Court were chosen as two of the most prominent cases; Diane Pretty on the grounds that hers was the first case to use the provision in the HRA 1998 to petition the court for assistance to die, and Tony Nicklinson as a later contrast to illustrate the extent to which human rights claims have developed and are currently being used to advance the argument for a right to die.

UK law and policy determines normative standards for the United Kingdom (except in some circumstances where provisions can vary between Scotland and England and Wales) but the UK also exists in a global context and, as such, can be influenced by international standards. An overview of assisted dying in other Western countries was indicated to demonstrate how

³² The End of Life Care Strategy 2008 is no longer in effect. Envisioned as a 10 year plan, the Strategy generated significant momentum and energy, which led to great improvements in end of life care. However population demographics and statistics about access to high quality end of life care revealed that more needed to be done. Currently, the 2008 Strategy is being refreshed to align it with the needs of the population and the changing health and social care landscape. NHS England are working in partnership with individuals and organisations, both statutory and voluntary, with professionals and the public, to develop a five year vision and plans for end of life care beyond 2015. The “Actions for End of Life Care: 2014-16” as an interim document sets out NHS England’s commitments to end of life care for adults and children (NHS England, 2014).

assisted dying had been incorporated into end of life provision and whether this may have implications for the UK. The Netherlands and the jurisdiction of Oregon in the United States were selected for closer analysis on the basis that assisted dying has been permitted here since the 1990s and there was readily available data, giving an indication of patterns and trends on assisted death.

Data collection and analysis

Law and policy documents were readily accessed on line and available for download. These included the Suicide Act 1961, Homicide Act 1957, Mental Capacity Act 2005, the NHS Constitution 2013 and End of Life Care Strategy 2008. Textual analysis of these documents and transcripts of the Pretty and Nicklinson statements of claim and judgements was carried out by reading the texts to examine where and how human rights discourses featured and had been used to determine or define end of life provision. In the legal cases of Diane Pretty and Tony Nicklinson, the focus was on how specific human rights principles had been used to challenge the existing status quo in order to achieve the right to an assisted death. As primary data, these documents were valuable sources that were largely untainted by perspective. Scott (1990 cited in Bryman 2008:516) presents a rigorous set of criteria against which the quality of documents might be gauged, these include “authenticity”, “credibility”, “representativeness”, and “meaning”. Document analysis of law and policy, and legal judgements, which form an official record, achieve these standards. The texts are genuine, free from distortion, recorded professionally and therefore representative and comprehensible.

4.2.2 Explore the prevalence of rights discourses in the historical and contemporary debates on assisted dying

Rationale for selection

The findings from analysis of UK law and policy documents prompted the next stage of the research process to explore more deeply how legal rights at the end of life were conferred in political institutions from the perspective of the law-makers. The House of Lords was chosen as a forum through which to examine historical and contemporary debates on assisted dying. This was primarily on the basis that, as part of the UK’s political institutions, the House of Lords has a key role in influencing legislation and their opinions can impact law and policy. In general, they are less politicised than the House of Commons and there are a range of political allegiances. Complex, moral and ethical issues are debated in an arena of “independent

expertise” (House of Lords, 2011a). Members have both time, inclination and ability to critically examine the issue of assisted dying in depth. Many are from legal, medical, and clerical professions that contribute a well-considered and enlightened perspective on this sensitive topic. Analysis of members’ comments in the debates illustrated their varied backgrounds.

The House of Lords first considered assisted dying, or voluntary euthanasia as it was termed then, in 1936 when they debated the Voluntary Euthanasia (Legalisation) Bill. Since then the issue has been debated in the Lords in 1950, 1967, 2003, 2004, 2006, and 2014. The House of Lords debates were also selected for analysis on the basis that these debates could be instrumental in mapping the discourses of dying over time and in illuminating how a concept of rights at the end of life may develop and operate within a changing social context. In this way, the historical and contemporary debates were identified as a potential source that could

...map specific discourses, especially as they document past and forthcoming (or foreshadow potential) changes in the legislation and/or the organisation of society and social institutions (Rapley, 2007:13)

The debates did “map specific discourses”. Analysis of the language used in the initial Voluntary Euthanasia (Legalisation) Bill 1936 and debate was selected to provide an insight into how early arguments on assisted dying were presented and discussed. These findings acted as a basis from which to identify and explore the use and development of rights discourses over time in comparison with later Bills and debates.

Parliamentary debates on assisted death in the House of Lords selected for analysis included the Voluntary Euthanasia Bill 1936, Patient (Assisted Dying) Bill 2003 and the Assisted Dying Bill 2014. The issue was also debated in 1950, 1969, 2004 and 2006. The reasons these debates were not chosen for in-depth study are briefly mentioned here. Following defeat of the 1936 Voluntary Euthanasia (Legalisation) Bill, the issue surfaced again on the political agenda in November 1950. The 1950s were not generally seen as a decade for moral reform in the aftermath of WWII. At this time there were pragmatic hindrances, including vociferous opposition, to the Voluntary Euthanasia Bill which was then withdrawn to avoid dividing the House (Kemp, 2002). The 1960s, by way of contrast, marked an era of personal freedoms including the decriminalisation of homosexuality and abortion in 1967 and changes to the Suicide Act in 1961. Lord Raglan took the opportunity to introduce a new Bill to legalise voluntary euthanasia in 1969 with the suggestion that public opinion was changing and there

was an increasing desire for “freedom of the individual” (House of Lords, 1969). His argument in this Bill was framed to extend provisions in the Suicide Act 1961 to permit requests for assistance to commit suicide (House of Lords 1969, col 1145). This Bill was defeated at Second Reading. It was not selected for analysis on the basis that the arguments primarily centred upon medical ethics and practice.

The issue then remained dormant on the House of Lords agenda until 2003 when Lord Joffe introduced a new Patient (Assisted Dying) Bill that mirrored the proposal by Lord Raglan to extend the liberty of dying or seriously ill individuals at the end of life. The arguments set forth in the 2003 debate were discussed extensively and had a significantly different focus to the 1936 debate, so for this reason were selected as part of the research design. On 10 March 2004, Lord Joffe introduced a second Bill (Assisted Dying for the Terminally Ill), the provisions of which were limited to terminally ill patients and included a requirement that all requests for assisted death must involve discussion of palliative care options. The Bill was given a Second Reading, and was then referred to the House of Lords Select Committee for examination but did not pass this stage (House of Lords, 2005).

Lord Joffe then proposed a third Bill on the issue in 2006. The Assisted Dying for the Terminally Ill Bill (ADTI) was similar to his earlier 2003 and 2004 Bills, but was modelled on the Oregon Death with Dignity Act 1997. It was also grounded significantly in empirical research following a nine-month enquiry by a House of Lords Select Committee to consider and report on the earlier Assisted Dying for the Terminally Ill Bill 2004. In comparison with earlier Bills, the 2006 ADTI Bill was narrower in scope and safeguarding mechanisms had been extended. Provision was solely for individuals with a terminal illness and the 2006 ADTI Bill in contrast to previous bills explicitly did not sanction any form of euthanasia, voluntary or otherwise. The emphasis on self-administration of lethal medication to end one’s own life shifted the balance from earlier proposals that saw medication administered by the attending doctor, to one that more closely represented individual agency. The 2006 debate was not selected for analysis on the grounds that it occurred only relatively shortly after the 2003 and 2004 debates and largely focused on similar issues. The main issue that dominated this debate and set it aside from the others included in the research, was the focus on the need for better and wider provision of palliative care. This debate was intended to reduce opposition from those who saw assisted death as a challenge that would affect government funding for palliative care services. Many

members' contributions praised the work of palliative care and expressed the desire for improved resources at the end of life.

Proposing three separate Bills for debate in the House of Lords within three years corroborated assisted death as a pressing and controversial issue. Pressure was mounting to accomplish a solution to this complex puzzle and this was fuelled by the efforts of Lord Joffe and others to maintain the issue on the political agenda. The Assisted Dying Bill 2014 proposed by Lord Falconer facilitated the most recent³³ debate in the House of Lords. This debate was selected for analysis because it was the one that reflected most closely the current sentiment on death and dying in UK society. I was also privileged to attend this 2014 debate in person and hear first-hand, the passionate contributions of proponents and opponents to the Assisted Dying Bill. Examining and comparing the transcripts of these debates has offered an important sociological insight into assisted dying, illustrating the prevalence of specific discourses through the contributions of members, a number of whom articulated and supported their arguments using language grounded in human rights.

Data collection and analysis

The proposal for the Voluntary Euthanasia (Legalisation) Bill 1936 was located in Dr Charles Killick Millard's 1931 publication *Euthanasia: A plea for the legalisation of voluntary euthanasia under certain conditions*. Transcripts of the Official Parliamentary Reports on the House of Lords debates in 1936 and 2003 were sourced through the British Library and the 2014 debate was accessed through Hansard. All debates were read and manual coding was chosen as a method to analyse the research data. Tonkiss (2004) highlights the benefit of coding to discover less obvious data, such as which ideas or representations cluster around key themes and how different concepts are spoken of and positioned within the text. Manual coding was preferred over computer coding at this stage of the research design on the basis that a substantial amount of extraneous ceremonial and polite language featured in members' contributions. A large proportion of text focused on acknowledging comments from other members rather than advancing their own arguments. This text could easily be identified, and disregarded, using manual coding without skewing the data and, at the same time, retain the

³³ In the 2016-17 House of Lords Private Members Bills ballot, a new Assisted Dying Bill proposed by Lord Hayward was introduced on Thursday 9th June 2016, no date as yet for second reading. This Bill proposes that requests for assisted dying are determined through the High Court (Family Division) and that lethal medication may be administered by registered nurses. "Assisted Dying Bill" Available at: <http://www.publications.parliament.uk/pa/bills/lbill/2016-2017/0042/17042.pdf> (Accessed 16.11.2016)

arguments and language used to express these in context. The texts were analysed to explore key themes and arguments with focus on the language used to express these.

The advantage of coding manually was that it provided a clear visual comparison of the arguments and language that defined each debate and how these have changed over time. The coding scheme arose from reading the data itself but was also influenced prior to this through the literature review and activities in the field. The literature illustrated how the end of life debate and policy had come to be defined primarily through concepts involving individual liberty and human dignity, but encompassing notions of suffering and vulnerability that could also be understood as human rights discourses. These were identified as important themes.

Themes and arguments for and against the legalisation of assisted death arose initially in the literature review and were confirmed through attendance in person at a number of planned events throughout 2013, 2014 and 2015. These included conferences and annual general meetings of both UK organisations that support assisted dying (Friends At The End and Dignity in Dying), Dignity in Dying affiliates (Healthcare Professionals for Assisted Dying and Inter-faith Leaders for Dignity in Dying) and their opponents (Care Not Killing). I attended two lobby days in Westminster in June 2013, one organised by Dignity in Dying and one the following day by the Care Not Killing Alliance. I attended a debate on medical ethics at the Royal College of Physicians organised by University College Medical Society in November 2013 titled "*This house would legalise assisted dying*" that attracted eminent speakers on both sides of the argument. Identifying themes and arguments in this way has supported my attempt at neutrality. It has ensured the coding remains grounded in the data and arises from the research itself.

4.2.3 Analyse how and why an organisation that campaigns to legalise assisted death use rights discourses

Rationale for selection

As a political forum, the House of Lords does not operate in a legal vacuum independent of outside influence. In each of the debates, there was a close collaboration between political figures and Dignity in Dying (DiD) as a national organisation that campaigns to change the law

on assisted dying. The vision of Dignity in Dying promotes “choice, access and control” at the end of life and their campaign efforts may have shaped perceptions of both the public and the law-makers on death and dying. Through collaboration with members of the House of Lords, DiD informed the content of proposed Bills and through the use of discursive strategies they may have influenced the terms of these debates. In this regard, the organisation were a natural focus for the next stage of the research.

Dignity in Dying is the larger of the two main UK organisations that actively campaign for the legalisation of assisted death with over 25,000 active supporting members. DiD were selected as the focus for a case study because they represent the loudest voice on assisted death, they are well- funded, have strategic allies and a prominent campaign presence that could shape the end of life debate. In addition, they are an historic organisation, founded in 1935. This grounds a social constructionist approach to the research in the same way as exploring the historic House of Lords debates; it provides an interesting analysis of how specific discourses have been used to define assisted death as the social context has shifted over time. The campaign activities of DiD have gained momentum and reach. They have collaborated with political and high profile figures, held regular meetings and events for their members, published campaign leaflets, newsletters and posters that were distributed in person and online, and held public demonstrations outside Westminster. Dignity in Dying was chosen to provide an intense and original case study that could “probe deeply and analyse intensely” (Cohen and Manion 1995:106). This case study method evaluated how, for what purposes, and to what extent human rights discourses were used by one progressive organisation in a new context. These findings could be helpful to illuminate how and why issues at the end of life are being defined and debated using rights discourses at this specific moment in time.

Data collection and analysis

Throughout the research period 2012-2016, I have written extensive field notes³⁴ on all meetings with Dignity in Dying and their affiliates. In relation to conducting the case study on DiD, I attended their Annual General Meetings on 21st May, 2013, 3rd June, 2014 and 9th June, 2015. I also attended meetings of their affiliated organisations including Healthcare

³⁴ These notes recorded the main points discussed at all events that I attended. There was usually one or more (guest) speakers and here I took lecture style notes. In addition to my notes, I included sections on my personal reflections, questions arising and actions to be taken together with recommendations for further reading or points of contact to advance my study.

Professionals for Assisted Dying (HPAD) conferences on 6th November, 2013 and 29th October, 2014, and the first InterFaith Leaders for Dignity in Dying (IFDiD) meeting on 20th May, 2013. I used these meetings as networking opportunities and to collect copies of their resources including newsletters, campaign publications and information booklets. The resources have slightly shifted focus over time but the content of the newsletters follows a fairly consistent pattern. Newsletter 2014, Issue 3 of 3 was considered to be a representative example and was selected for more detailed analysis during the period of conducting the case study. This resource also proved conducive to exploring the work by Miller (2010) in relation to rights-framed approaches in the context of a campaigning organisation, being particularly timely in the wake of the Assisted Dying Bill 2014 that DiD had been closely involved with.

As part of the case study, I also visited the Dignity in Dying offices in London and conducted informal interviews³⁵ with their Director of Campaigns and Communications on 15th January, 2014 and their Public Affairs Manager on 9th September, 2016 to discuss the approach, activities and planned campaign tactics of DiD. Following personal contact with the leaders of affiliated organisations, I conducted one to one interviews with Professor Ray Tallis, HPAD Chairman 26th April, 2013 and Rabbi Dr Jonathan Romain, IFDiD leader 2nd May, 2013 by telephone with informed verbal and written consent given. Each telephone interview lasted approximately 40 minutes, they were recorded and transcribed immediately following the interviews. These early interviews were intended to explore individual motivation and experiences to gain a better understanding of how the affiliated organisations support the work of DiD and to assess whether the rhetoric to support the affiliates' objectives was underpinned by a human rights discourse or reflected their own areas of interest.³⁶

³⁵ I had been made aware of the reluctance of Dignity in Dying employees to speak on record with the UK media and social researchers and for this reason these two interviews were approached as informal and used indirectly to inform my analysis. Verbal consent was given to reference their views in general rather than specific terms. These interviews were not recorded, instead jotted notes were taken during the interviews and written up afterwards.

³⁶ Healthcare Professionals for Assisted Dying (HPAD) chaired by Professor Ray Tallis and Inter-Faith leaders for Dignity in Dying (IFDiD) led by Rabbi Dr Jonathan Romain were both founded in 2012. In 2014, Disabled Activists for Dignity in Dying (DADiD) was launched to represent the voice of disabled people led by disability rights campaigner, Greg Judge. The establishment of these organisations was an attempt to extend the reach and introduce the objectives of DiD to a wider audience and reduce longstanding opposition to assisted death, particularly on faith and medical grounds. HPAD and IFDiD aim to recruit new members specifically within these areas and, in doing so, strengthen the key arguments of Dignity in Dying. The telephone interview with Rabbi Romain revealed that he expressed his arguments for legalising assisted death, not through rights discourses, but through faith-based and compassionate discourses. His contribution to the campaign for Dignity in Dying, as an influential religious leader, argued that religion and an assisted death could be compatible. The interview with Professor Tallis demonstrated how he prioritised a discourse of compassion and acting in the best

In addition, independent examination of the DiD website as mediated communication (available at dignityindying.org.uk) has provided extensive and rich data. The DiD home page currently lists subsections “About us/ News/ Your rights/ Assisted dying/ Resources/Personal stories/Support us” (DiD, 2016). Personal stories are narratives written by individuals who are dying, or close family members writing after the death of a loved one. These were selected for analysis to provide a powerful and emotive insight to the research question. Smith and Schaffer (2004:1) claim that “over the last 20 years, life narratives have become one of the most potent vehicles for advancing human rights claims”. The discourses with which vulnerable, dying members of the public and their families articulated their lived experiences were identified as important and indicative of how one “right to die” organisation strategically used these voices to frame and further their campaign objectives.

The personal stories on the DiD website are divided into different regions. Stories from London and the South regions were selected for analysis primarily to reflect the geographical location of the study and correlate with the area within which focus group participants lived. This provided a degree of consistency and while the data gathered may be less transferable or replicable due to it being geographically representative, it did contribute a rich analysis that may be useful for a comparative study at a later date. In June 2016, the DiD website issued a disclaimer stating that the personal stories “reflect the views of the authors. The views of Dignity in Dying may differ” (DiD, 2016). Meeting with the Director for Public Affairs, he confirmed that the personal stories had not been edited by staff at Dignity in Dying and were based on individual experiences. The personal stories may not have been edited, but it is important to acknowledge that they have been curated for a purpose, namely to reflect the ethos and objectives of DiD. In total, 36 personal stories from London, the South- East, and South-West were available and selected for analysis at <http://www.dignityindying.org.uk/personal-stories/> (Last accessed 13.05.14). These were referenced by the name of the contributor for identification purposes.

interests of the patient that reflect the guidelines for medical treatment. In this way, he argued that medicine and assisted death could be compatible. Analysis of the data from these interviews was not included in the case study write-up because the nature and extent of the relationship between DiD and IfDiD/HPAD was not easily determined and could only provide an indication rather than true representation of how these affiliated organisations supported the objectives of DiD.

In order to analyse the data rigorously, Gibbs (2007:42) recommends both reading a printed version of text and using a computer software program,

...paper allows me the kind of creativity, flexibility and ease of access that is important at the early stage of analysis. I then transfer the coding ideas into the electronic version of the project in order to continue the analysis.

Intensive reading then computer coding facilitated a more detailed and diverse analysis than purely description. Firstly reading the text of the personal stories lent continuity to individual narratives, allowed time to appreciate the perspective of who was telling the story, put into context the background history together with the illness trajectory, and to better appreciate the lived experience. The computer software program NVivo10 was then used to identify the most frequently used words and analyse the context in which they appeared.³⁷ A word frequency query was conducted initially to identify key words that predominantly featured in the personal narratives and to consider the extent to which they were representative of human rights discourses. These words and themes were subsequently used to organise the coding scheme. The associated text was coded at nodes and these were then analysed in order of the most frequently occurring first.³⁸ This reduced bias in classifying the nodes and also supported the advice for qualitative researchers that “coding should remain grounded in the data in the transcript” (Gibbs, 2007:52).

Critical reflection

Tonkiss, (2004) argues the benefit of coding is to discover less obvious data, for example, which ideas or representations cluster around key themes and how different concepts are spoken of and positioned within text. Critical reflection of using NVivo10, in addition to reading the printed text and using manual coding, concluded that it was a beneficial tool to help analyse discourse and provide a “multi-layered interpretation of the data” (Gibbs, 2007:140). Practical advantages of the NVivo10 programme included the ability to overview and represent data visually in easily accessed and stored format such as a Tag Cloud and coding information at nodes enabled data to be found efficiently under organised lists. Generic critique of computer coding is that the context of what is said may be lost; fragmenting data loses the narrative analysis (Bryman 2008, Seale, 2004). The quality of discourse analysis is also

³⁷ NVivo analysis was used extensively to query related themes and examine correlative factors to specific themes that included age, gender, and relationship. However word frequency most comprehensively illustrated the ways in which members of the public articulated their end of life experiences, and therefore this featured in the write-up.

³⁸ Respectively “death”, “dying” and “assisted” were the most frequently occurring words after “life”, but they all occurred in context and were purely descriptive so were not written up as an independent section for analysis. References to the Swiss clinic “Dignitas” occurred as the 7th most frequent word but, for similar reasons was not included.

dependent upon the quality of the coding scheme that may be tainted by researcher bias. Gibbs (2007:52) warns the “dangers of coding...is importing your own motives, values and preoccupations into the codes and analytic schemes you construct”. Personal or emotional bias in this case study involved selecting and interpreting the words assigned to each coded node. This could have been minimised by two researchers coding at nodes and comparing their results.

4.2.4 Assess the extent to which public perceptions on death and dying invoke rights discourses

Rationale for selection

Death and dying are deeply personal topics grounded in human experience, values and beliefs. Focus group discussion was selected as part of a qualitative approach to the research to contrast with polling data, survey responses and clinical studies on the basis that it can provide richer data for analysis.³⁹ Participants spent time defining, discussing and articulating their perspectives. They used examples to support these and drew on personal experiences using familiar language which demonstrated how central human rights discourses were to shaping their own perceptions of death and dying. Through this form of social interaction, focus groups allowed space for participants to reflect on the contribution of others, develop their own thoughts and return to concepts discussed in their own time. The use of focus groups in the research design was grounded in a social constructionist approach and used to illustrate how opinions, attitudes and accounts are socially produced and, to an extent, shaped by interaction with others. The ways in which participants articulated and justified ideas in relation to others reflected the interactive and communicative nature of social action and meaning (Tonkiss, 2004).

Members of the public associated with Death Café Hampstead were selected to participate in focus group discussions on the grounds that these participants were an unexplored subject

³⁹ Focus groups, were preferred over personal interviews as prior personal experience of discussing sensitive issues had shown that comments were more likely to be tainted by the values of the researcher in an intense one to one proximity. Group discussion better enabled people to express their views in a way that was not encouraged, inferred or pre-judged by the researcher. In comparison to personal interviews, they seemed less intimidating, primarily because the larger group situation relieved the intensity upon one individual when discussing emotive issues and the emphasis on a direct response that could have been suggested by the intimacy of a one to one interview.

group that complemented the novelty of the research design and were both accessible and available as research subjects. Prior to conducting the first focus group for the purpose of this study I had facilitated monthly small group discussion at Death Cafes held at the Café Rouge in Hampstead, London over a period of 12 months and, as Silverman (2013:215) notes,

...if you are contemplating fieldwork it simplifies access if you draw upon your existing circle of contacts. Trying to enter a new field is likely to involve time-consuming negotiations and may end in failure, particularly if you want to research an ethically sensitive area.

The other advantage of conducting research on this accessible and “existing circle of contacts” was that individuals connected with Death Café had voluntarily registered an interest in speaking about the sensitive issue of dying and had met to discuss this in a group environment. On this basis, they may have been familiar and more comfortable with articulating deep or intimate feelings and experiences on a subject that is intensely personal and this minimised the ethical implications, considered below. The existence of social initiatives, that include Death Café are indicative of how issues associated with end of life have come to be discussed more openly in the public domain and are facilitating opportunities for research into an area that has, until recent years, been “hidden” or “taboo”.

Data collection and analysis

To recruit focus group participants, a list of Death Café attendees of approximately 400 individuals were emailed in September 2014 with an invitation to participate in the study, a letter of information and consent forms (see Appendix Two). Individuals responded via email or telephone to register their interest and suitable times were suggested. Three group discussions were held at the usual Death Café venue on evenings in September and October 2014, and February 2015. The format for each session was the same. On arrival participants were greeted, offered drinks and light meals from the Café Rouge menu and any incurred travel expenses were reimbursed. Participant demographics across the three groups are displayed in the table below.

Figure 4.4 Focus group demographics

Discussion date	Females	Males	Profession	Age range	Serious Illness
<i>September</i>	6	1	1 psychotherapist, 1	30-64	1 person,

<i>2014</i>			property manager, 1 program manager, 1 healer, 1 artist, 1 teacher (retired) 1 not recorded		wheelchair user
<i>October 2014</i>	1	1	1 IT manager (retired), 1 counsellor,	60-65	None
<i>February 2015</i>	5	2	2 academics (1 retired), 3 psychotherapists, 1 teacher (retired), 1 screenwriter	32-75	1 person, in remission

Questions and prompts were standardised to enhance reliability and replicability of the study and improve comparability across the groups (Morgan, 1996). A schedule of questions is found in Appendix Two. A funnel approach was used, beginning with an open ended question “What does dignity mean to you?” that allowed time for participants to become familiar with each other and tease out some key concepts⁴⁰ (Morgan, 1998). Key topics included concepts of personal liberty, human dignity, suffering and their understanding of a right to die that were structured around specific phrases, such as “Do you think people should have a right to ask for assistance to die?” The questions chosen were identified as important through the data as it arose in the previous stages of the study and then worded following a small pilot study. Few questions and minimal prompts were used to allow adequate time for all participants to be heard without undue interference. It was intended that by reducing my personal input, less bias would be detected (Morgan 1998, Krueger 1998a).

Critical reflection

Critical reflection on using focus groups as a research method in this study accepts that there were limitations to the generation of theory when analysing a small sample group (16

⁴⁰ There are very few available courses or literature designed to teach moderating skills. Much depends on the personality and experience of the researcher and recommendations were found in Krueger (1998a, b) Morgan (1998), Langer (1978, cited in Stewart and Shamdasani 1990:78) and Barbar and Kitzinger (1999:13).

participants in total⁴¹ excluding myself) but these preliminary findings could be used as the basis for conducting focus group discussion on end of life issues with other samples of participants. Having experience of attending Death Café Hampstead suggests that at some level all participants were comfortable with, or interested in, speaking about death and dying. In this way focus group participants were not considered to be representative of the public and the findings of the data cannot be assumed as indicative of wider opinion. However, it does inform the centrality of human rights discourses from a limited public perspective. The outcomes of group discussions based on how they engaged with the topic may have varied if the sample of participants were selected differently. For example, focus groups conducted in a different geographical location, with particular groups of individuals, or solely with male or female participants.

Stewart and Shamdasani (1990) criticize the usefulness and validity of focus groups in general claiming that participants can be influenced by one another and by the moderator. Group cohesiveness and compatibility depends on how individuals feel about communicating their views, and intrapersonal variables and personality or behavioural disposition also influences this (Stewart and Shamdasani, 1990). In a group of people, particularly in relation to emotive issues, one cannot predetermine the personal backgrounds of participants, their willingness to speak in a group situation or how they interact with others. Walter and Murray-Parkes (2015) argue that in group discussion there remain conversational norms around death and dying and there may be more or less acceptable images and metaphors that can be used to discuss death. Ways to overcome this are discussed below in relation to ethical sensitivity.

4.3 Ethical considerations

Research on death and dying in general is a sensitive, individual, emotionally laden and sometimes unfamiliar topic. The issue of assisted death in particular is controversial. In

⁴¹ On a practical note, one disadvantage of holding focus groups, especially with unpaid volunteers, is that attendance cannot always be predetermined. The first and third groups both had 8 participants including myself. The second focus group should have comprised six participants and myself, seven in total, but I received four cancellations on the night by email and text message due to emergencies that included hospitalisation, death of a close friend, cancellation of childcare agreement, and flooding due to a plumbing leak. This unexpectedly left only two participants other than myself but at their request we decided to continue the discussion, which was interesting and covered a wide range of topics. Both participants were able to speak in depth about their own experiences, in particular the deaths of their parents. During this discussion I was also more involved as participant, it was a conscious decision pre-empted by feeling that it was “the right thing to do”.

complex dilemmas such as these, it can be difficult to appear impartial. The opinions of the researcher may be influenced by personal experiences, cultural backgrounds, values or beliefs and the findings of the data as it emerges during the research process. At the outset of the research period, I attended lobby days and engaged in conversation with the leaders of organisations that campaigned both for and against the legalisation of assisted death, before selecting Dignity in Dying for analysis. In writing up telephone interviews with Dignity in Dying affiliates, the House of Lords debates and focus group discussions, I have sought to accurately and fairly record their views which are considered representative. In addition, I have no declaration of interest. I am not affiliated with any organisations that campaign for or against assisted death and I have not experienced any requests to assist a death personally nor known any family members or friends who have died in this manner prior to completing this study.

Definitions of sensitive research vary according to age, culture and situation. Renzetti and Lee (1993) argue that sensitive involves “intimate, discreditable or incriminating” topics that delve into deeply personal experience and may be emotionally demanding, and on this basis warrant specific ethical considerations. In particular, the part of the research design involving focus group discussions was both intimate, personal and had the potential to be emotionally demanding or upsetting. Therefore due ethical procedures were followed in order to minimise harm to both participants and the researcher during the study. This initially involved gaining ethical approval for conducting focus group discussions through the Kingston University Faculty Ethics Committee prior to emailing potential participants. Considering that focus group participants were familiar with Death Café, some may have had recent bereavement experiences or personal crisis that may prove distressing to speak about in a group environment, a brief telephone conversation was undertaken with all participants who contacted me to register their interest in the study. This served as a first point of personal contact to familiarise participants with the study, explain the format of the evening and provide them with an opportunity to raise questions or discuss any potential issues beforehand.⁴² Prior to this, participants had been sent an invitation and letter of information that detailed the procedure and intention of the study, proposed dissemination and contact details of my supervisor in case of further questions or complaints. On arrival at the Café Rouge, it was a priority that all participants felt comfortable. Everyone was greeted personally, provided with a menu to peruse plus travel expense and consent forms to fill out allowing

⁴² For example, I agreed with one wheelchair bound participant to arrange an access ramp at the Café Rouge entrance and conduct the discussion downstairs rather than the usual upstairs meeting venue.

them time to familiarise themselves with their surroundings and other participants before the discussion began. This was conducted in a professional, but relaxed atmosphere which encouraged sharing their thoughts and experiences in a safe, respectful environment.

The British Sociological Association Statement of Ethical Practice (2002) suggests researchers of sensitive topics should “consider carefully the possibility that the research experience may be a disturbing one” and this applies both to themselves and research subjects. Individuals participating in focus group discussions were informed at the time of the study that should they wish to speak further on any issues arising or causing them distress from participation in the group discussion then I could arrange this with a registered psychotherapist (known to myself and procured through prior verbal agreement). For my own purposes, and on the advice of the Ethics Committee Chair, I had contacted and spoken with the University Faith Advisor regarding pastoral support during the study if needed. Quite surprisingly, over the research period, five individuals (including one focus group participant) revealed to me in detail their involvement in a partner, or loved ones suicide⁴³. These individuals did not fully disclose their names or personal contact details. In each case it was interesting to note they were confident that their assistance was given solely out of compassion and at the request of the dying individual who was suffering unbearably. In these five cases, two were subject to a routine police investigation, but no charges were brought and the assistance described by the focus group participant took place in another country.

Guidelines on obtaining informed consent are suggested in the literature and these include advice by the General Medical Council (GMC, 2002) to “seek permission to make the recording and get consent for any use or disclosure” and to “give participants adequate information about the purpose of the recording when seeking their permission” together with ensuring that “participants are under no pressure for the recording to be made”. These guidelines were duly followed. At the time of sending the invitation and letter of information, recipients on the Death Café mailing list also received a consent form to allow time for them to read this before attending the discussion. Consent forms were signed as they arrived for the discussion group and they were asked if they had any questions or would like further clarification regarding this procedure.

⁴³ I have sought guidance from both a Deputy District Judge (Magistrates Court) and the Kingston University Faculty Ethics Committee on the ethical and legal obligations resulting from these disclosures.

Maintaining confidentiality and securing data is also important when researching sensitive issues to reduce potential harm to participants. Lee (1993:164) argues that “[r]obust techniques for preserving confidentiality are indispensable”. When contacted initially by interested participants for the study, only their first names and a telephone number to use in case of emergency were recorded and on attending the discussion they were then asked to provide the additional demographic information tabled above. The group discussions were recorded using a digital audio recording device and transcription of each discussion recorded the words used by participants *ad verbatim*. In writing up the data, quotes were referenced by participants’ sex and age to provide an indication of whom they were but to maintain confidentiality, for example “Female, aged 60”. Another aspect of confidentiality includes regulation through the Data Protection Act (1998), which lays down guidelines for the processing of personal information. The digital recordings of each focus group discussion were not copied. Each transcribed discussion was stored on my home computer and used only for the purposes of this research that will be deleted on completion of the thesis. The audio recorder was returned to Kingston University Loans Department with the assurance that all material is immediately deleted as standard procedure.

Conclusion

This chapter has provided a detailed account of the different stages of the research undertaken throughout 2012-2015. Premised on a broad social constructionist approach, a qualitative research strategy was adopted using discourse analysis to explore the centrality of human rights discourses to the UK end of life debate and policy on assisted death. In qualitative research, the emphasis is upon the validity, reliability and replicability of the research design (Bryman, 2008). An important aspect of validity rests on claims of neutrality of the researcher, but in complex dilemmas it can be difficult to appear non-biased. Neutrality was attempted in this study by way of selecting a range of different texts from a variety of sources to provide a comprehensive analysis of the research question and relating the findings specifically to human rights frameworks.

At each stage of the research design, the rationale for selection and the process of data collection and analysis has been discussed to demonstrate reliability and replicability. Document analysis of law and policy and coding of the transcripts of the historical House of Lords debates is easily replicable, notwithstanding a degree of variation in the coding scheme of the latter that could be minimised by more than one researcher undertaking the same

study. This could also be said for NVivo coding of the personal narratives used in the case study analysis of Dignity in Dying. With regard to focus group discussions, the contributions of participants is liable to variation dependent upon personal backgrounds and the nature of interaction with other participants. Group dynamics can also be influenced by the personality and approach of the researcher. However, the practical process of recruitment, questioning format and information given was, in this research, consistent to enhance reliability and replicability of this study.

The thesis now turns to the data chapters where each of the four objectives are addressed through the research. The first of these data chapters provides an insight into law and policy provision for options at the end of life in the UK to set the legal context for the debate. Analysis of these documents and the legal petitions of high profile right to die cases illustrates the ways in which human rights principles are currently featuring in the debate and policy.

CHAPTER 5

Law and policy

The purpose of this chapter is to explore the current legal provision for assisted death and to illuminate *where* and *how* human rights discourses feature in UK end of life law and policy. The

law has a regulatory function. Customary law and human rights principles determine common practice and thereby influence normative standards whilst Government healthcare policy strategically defines and shapes the delivery of services and care at the end of life. This chapter, in keeping with the rest of the thesis, refers to a UK context and provides a broad understanding of UK law. Where law or policy in relation to that of England or England and Wales differs, this will be specified. Both European Union law and the European Convention on Human Rights 1950 applies to both Scotland and Northern Ireland as it does to England and Wales by virtue of their position as UK constituents.

This chapter is divided into four sections. It begins with an overview of UK law considering statutory provision for assisting a suicide as defined by the Homicide Act 1957 and Suicide Act 1961. The role of the law in common and medical practice is questioned and the ambiguity of exercising discretion in hard cases is noted. This section also considers the implications of the relatively recent HRA 1998 with regard to its impact upon legal process and institutional practice. The second part of this chapter examines the cases of Diane Pretty and Tony Nicklinson to assess their use of key human rights principles in supporting their legal appeals for assistance to die. It considers the extent to which their arguments have challenged the interpretation and application of legal rights. The involvement of the European Court of Human Rights in these prominent cases highlights that the UK exists within a wider context before the third section of this chapter provides an overview of other jurisdictions where assisted dying is legal. High profile cases are important in that they can set legal precedent and provoke statutory changes, but Government policy on end of life care shapes practical provision for the dying. Policy discourses are explored in the fourth section through the NHS Constitution 2013 and the Department of Health End of Life Care Strategy 2008.

5.1 UK Law

This section illustrates the mechanisms of law in relation to the current legal status of assisted death through statutory provision in the Homicide Act 1957 and the Suicide Act 1961. Examination of these instruments reveals three areas of controversy in the law: the lack of partial defence to murder; the ambiguity of applying discretion in hard cases; and the dubious differentiation between killing/letting die under a medicalised model of care. This section also explores the role of the HRA 1998 and ECHR 1950 as applied in the UK.

5.1.1 Homicide Act 1957 and Suicide Act 1961

There is no provision for the figurative terms “right to die” or “assisted dying” in statutory legal instruments which explains their absence in this section. In law, assisted death can include voluntary active euthanasia and assisted suicide. The former involves a third party ending the person’s life and the latter, a third party providing the person with assistance to end their own life. Both actions necessitate that assistance is requested and consent given. Voluntary active euthanasia is killing classified as intentional killing under the Homicide Act 1957 and this carries a mandatory life sentence on conviction.

Under the Homicide Act 1957,⁴⁴ any person assisting a death could be accused of committing the crimes of murder, manslaughter or complicity in suicide. Section 4(1) and 4(2) of the Homicide Act 1957 relate to the offence of aiding and abetting suicide by stating

It shall be manslaughter, and shall not be murder, for a person acting in pursuance of a suicide pact between him and another to kill the other or be a party to the other being killed by a third person (Homicide Act 1957, S4(1)).

Where it is shown that a person charged with the murder of another killed the other or was a party to his . . . being killed, it shall be for the defence to prove that the person charged was acting in pursuance of a suicide pact between him and the other (Homicide Act 1957, S4 (2)).

The 1961 Suicide Act in England and Wales decriminalised the act of suicide but retained punishment of up to 14 years’ imprisonment for the aiding, encouraging or counselling of suicide under section 2. According to this law, any individual (including close family) involved in the act of assisting a suicide even if this was at the repeated request of a competent individual with a clear and intentioned wish to die would breach the Suicide Act 1961. Section 2(1) of the Suicide Act 1961 implies criminal liability for complicity in assisting a suicide when a person aids, abets, counsels or procures the suicide of another and this is defined when

(a) D does an act capable of encouraging or assisting the suicide or attempted suicide of another person, and

(b) D's act was intended to encourage or assist suicide or an attempt at suicide.

⁴⁴ Section 1 of the Scotland Act 1998 established a range of devolved powers so that the Homicide Act 1957 is not consistently applied in Scotland and the Suicide Act 1961 specifically only amended the law in England and Wales (Scotland Act 1998).

In 2009, the Coroners and Justice Act amended these provisions with the addition that the person assisting may not necessarily be known to, or identified by, the individual wishing to commit suicide, and on the condition that “[N]o proceedings shall be instituted for an offence under this section except by or with the consent of the Director of Public Prosecutions” (Coroners and Justice Act 2009). The role of the Director of Public Prosecutions in clarifying the law on assisted suicide is considered below.

Analysis of the law revealed a stark contrast between the acts of assisting suicide and killing as manslaughter or murder. Under section 4(2) of the Homicide Act 1957, persons involved in a suicide pact or assisting the suicide of another, in the context of a suicide pact, may be charged with the offence of manslaughter carrying a lesser criminal sentence than murder. Keating (2016) critiques this discrepancy in law to argue that a new partial defence to murder is needed that focuses on the motive for killing. Keating (2016) claims the law as it stands is failing individuals. Her proposal would make allowance for a “caring, relational response” grounded in *compassion* and a desire to end human suffering. The late Margo MacDonald MSP also suggested amendments to the current law, proposing in the Assisted Suicide (Scotland) Bill 2013 to remove criminal and civil liability for assisting suicide and intending to “make it lawful, in certain circumstances, to assist another to commit suicide” (Assisted Suicide (Scotland) Bill 2013).

The police, as UK law enforcement officers, have a duty to investigate all allegations or suspected cases of assisted suicide. From 1 April 2009 until 1 October 2014, there were 101 cases referred to the Crown Prosecution Service (CPS) by the police which had been recorded as assisted suicide or euthanasia. Of these 101 cases, the CPS decided not to proceed with 69, and, in 16 cases, no further action was taken by the police (CPS 2014). Five cases were referred onwards for prosecution for murder or serious assault and there are currently 10 ongoing cases (CPS 2014).⁴⁵ Only one case of attempted assisted suicide, where the individual survived, was successfully prosecuted in October 2013, that of Kevin James Howe. Mr. Howe received a custodial sentence from Durham Crown Court of 12 years imprisonment for “doing an act intended to assist someone to commit or attempt to commit suicide”. In this case, the

⁴⁵ For a comprehensive list of published decisions see CPS (2014) “Assisted suicide” Available at: http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html (Accessed 01.12.14)

assistance involved supplying petrol to a friend who suffered 90% burns on setting himself alight (Law Pages, 2015). His sentence was later reduced on appeal in February, 2014 to 10 years' imprisonment (Law Pages, 2015).

Investigation of friends or relatives assisting or encouraging a suicide are often considered "hard cases", especially if they arise from compassion or the desire to alleviate suffering in the context of serious or life-limiting illness. If, under a particular rule of law a prosecution cannot be pursued, then it becomes the responsibility of the Director of Public Prosecutions (DPP) to exercise discretion and reach a decision on whether to prosecute or not. Hard cases, particularly those where individuals make heartfelt requests for assistance to die to relieve intolerable suffering, expose the law as a blunt instrument. They require the DPP to consider whether a prosecution is necessary in the public interest. This discretionary decision, taken in accordance with the code for Crown Prosecutors may involve a range of acceptable answers that necessitates the otherwise strict application of law to be interpreted by applying tolerance and common sense. In this way, the application of discretion especially in relation to hard cases is a relative concept. This critique was highlighted in 2009 through the petition of Debbie Purdy. Her application to the High Court helped to clarify the law on assisted suicide. This appeal was then heard in the House of Lords. It was based upon the

...absence of a crime-specific policy, identifying the facts and circumstances that the Director of Public Prosecutions would take into account when deciding whether to prosecute an individual for assisting another person to commit suicide (R (*on the application of Debbie Purdy*) v. *Director of Public Prosecutions* [2009] UKHL 45).

In response to this appeal the Director of Public Prosecutions, Keir Starmer, acknowledged that the degree of consent and assistance between the deceased and the person accused of assisting or encouraging a suicide was particularly difficult to ascertain and formulated a *Policy for Prosecutors in Cases of Encouraging or Assisting Suicide* (2010).

The *Policy for Prosecutors in Cases of Encouraging or Assisting Suicide* (2010) aims to reduce the ambiguity of individual discretion in hard cases by listing 16 factors in favour of prosecution and 13 factors militating against. Circumstances in which prosecution is more likely include: if the suspect was acting in his or her capacity as a medical doctor, nurse, other healthcare professional or a professional carer (whether receiving payment or not); if the suspect has assisted more than one victim; or received payment for the action (*Policy for Prosecutors in Cases of Encouraging or Assisting Suicide*, 2010). Individuals providing only "minor encouragement or assistance" or attempting to dissuade the person from suicide, acting wholly out of compassion and not for financial gain, and where the deceased has made

known their wish to die are less likely to face prosecution if assisting a person to die (*Policy for Prosecutors in Cases of Encouraging or Assisting Suicide*, 2010). One could argue that degrees of ambiguity still exist in this policy and the clause that denotes more likely prosecution of healthcare professionals assisting a suicide may increase the pressure upon non-qualified individuals to provide amateur assistance.⁴⁶ Alternatively, the policy could be regarded as adequately rigorous and sympathetic in acknowledging that there are some complex cases involving human suffering and indignity where genuine compassion provides the motive for assisting a suicide. More importantly, this policy embodies a discretion in the current law as there appear to be circumstances under which individuals can avoid prosecution for encouraging or assisting suicide, evidenced by CPS statistics. The *Policy for Prosecutors in Cases of Assisting or Encouraging Suicide* 2010 through lack of prosecution tolerates assisted suicide by guarding the exercise of discretion.

5.1.2 Killing or letting die

Examining the distinction between killing and letting die draws attention to another area of contestation in the law. Methods of letting patients die include the withholding or withdrawing of medical treatment and this action is both legally and professionally permissible. Where treatment is withheld or withdrawn, decisions likely to lead to death are taken by the attending doctor when the risks or burdens would outweigh the benefits of treatment, or under medically hopeless conditions, for example, when withdrawing respiratory support from a patient who is unlikely to recover and unable to breathe on their own (see *Airedale NHS Trust v Bland* [1993]1 All ER 821 HL, for the first England and Wales case or *Central Manchester University Hospitals NHS Foundation Trust v A and others* [2015] EWHC2828 (Fam) for a more recent judgement). Where the patient is allowed to die through withholding or withdrawing of artificial ventilation, fundamental organ failure is usually registered as the primary cause of death. In such cases as these, death is accelerated and knowingly allowed to happen by withholding medical treatment or nutrition at the discretion of the attending doctor. Based on their medical knowledge and clinical assessment, decisions are made in what is deemed to be the best interests of the patient.

⁴⁶ In October 2014, the DPP issued a policy update to guide the exercise of discretion and clarify the role of healthcare professionals. A footnote at paragraph 43 highlights that prosecution is more likely if the suspect was acting in "his or her capacity as a medical doctor, nurse or other healthcare professional...and the victim was in his or her care" (*Policy for Prosecutors in Cases of Assisting or Encouraging Suicide*, 2010).

The medical professional bodies issue good practice guidelines for doctors and guidance for decision-making in critical cases (see BMA 2001, GMC 2002).⁴⁷ However, the practice of withholding or withdrawal of treatment raises questions on both the legal and ethical distinction between letting die and killing. It highlights, from a Foucauldian perspective, the superimposition of knowledge and power relations under a medicalised model of care and intensifies the debate over who is sovereign over life and who controls our bodies. Specifically with regard to assisted dying, it incites discussion on the extent to which withholding and withdrawing treatment is comparable to death being actively encouraged, for example by prescribing a higher than usual, and subsequently lethal dose of morphine or barbiturates.

Acts of ending life which involve letting die following medical evaluation, do not usually involve criminal investigation and thus are effectively legalised in a similar manner to the act of killing through the doctrine of “double effect”. The double effect principle is enshrined in both criminal law and medical ethics and practice, where in legal terms there is a differentiation between “intention” and “foresight”. A typical example to illustrate this involves the physician prescribing, or administering morphine, or other opiates, with the aim to alleviate pain and control symptoms at the end of life. However, the high doses needed in cases of serious illness can, on occasion, induce coma and result in death, the consequences of which are classified as either *intended* or *foreseen* (Jeffrey, 2009: 43). This legal differentiation respects the professionalism and experience of the prescribing physician but critics highlight this distinction between intention and foresight as arbitrary. They argue that medical training adequately teaches the inevitable consequences of action and when death is an almost certain consequence of action it must be regarded by the law as criminal intent (Magnusson 2006, Williams 1958). Studies by Seale in 2006 reveal that 30% of all UK deaths witnessed by a medical doctor are preceded by the withdrawal of treatment, and 33% of deaths from double effect of the administration of medicine, suggesting this practice is not uncommon (Seale 2006:653-9).

A court or jury has the responsibility to determine whether an offence has been committed with intention or foresight through the Criminal Justice Act 1967, section 8. If the primary intention of the physician was to cause death, criminal prosecution is likely. However, if the

⁴⁷ More specifically, GMC guidance on decision-making for doctors can be found in *Treatment and care towards the end of life: good practice in decision-making*, in place since May 2010. Available at: www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp (Accessed 13.11.16)

physician foresaw death as a natural and probable cause of his actions and this was in line with his professional judgement, then the requisite of criminal intent is absent, and punishment by law is unlikely (Criminal Justice Act 1967). In effect, doctors *do* assist patients to die through both their acts and omissions that are sanctioned through section 8 of the Criminal Justice Act. Letting die and the doctrine of double effect permits the ending of life under medical authority on the basis of paternal decision-making where these actions and omissions are deemed to be in the patients' best interests. Contributions by Foucault (1973, 1977) and Turner (1995) discussed briefly in section 2.1.1 resonate here. The medicalised model of care currently practised in the UK allows the medical profession and healthcare law and policy to dictate behavioural norms articulated through specialised discourses. However, the increasingly liberal shift towards independent rational choice and the maintenance of human dignity underpinned by the salience of rights in an end of life context are issuing a significant challenge to medical authority on a number of levels.

5.1.3 Human Rights Act 1998

In November 1998 the Human Rights Act (HRA) received Royal Assent. It enshrined the principles of the 1950 ECHR within UK law. Article 6 enacts a requirement that all public authorities in the UK must take the provisions of the 1950 ECHR into account when formulating policies and procedures and provide effective remedies before national authorities for breach of these provisions (De Smith, Woolf and Jowell, 1999:12). This includes the NHS as a public authority, which has legal duties and responsibilities to act in a manner compatible with the Convention rights. The HRA 1998 has constitutional significance with regard to end of life decision-making because it embraces fundamental rights and freedoms that are generally deemed to reflect a democratic society. These include: rights to basic dignity; to participate in decisions affecting liberty; rights of expression, and equality rights (De Smith, Woolf and Jowell, 1999:14). In addition, section 6(1) of the HRA provides a method for which individuals in complex cases, including requests for assistance to die, also have the option to petition a court to challenge a decision already made through the process of judicial review as illustrated by the cases of Diane Pretty and Tony Nicklinson discussed below.

The process of judicial review in the UK law courts functions to ensure the reasonable exercise of power and to regulate democratic accountability. The judicial decision-making process can also further define or explain human rights principles and determine whether states' legislation is compliant with these principles. Cases on assisted dying heard in the European Court of

Human Rights in Strasbourg can provide a narrow analysis of whether UK legislation is compliant with European human rights law and these set UK government policies in a wider context. The function of the law is to determine acceptable or punishable behaviour, supposedly to reflect the values of society, but in certain or exceptional circumstances it may be necessary to rely on the judiciary as a filter to *interpret* European and UK laws according to individual social and cultural merit on a case by case basis. In these instances, the judiciary apply “principles of statutory interpretation”, which are based on a generally accepted notion “that gaps in the statute may be filled by analogical reasoning, on the footing that legislature might be presumed to have desired to cover such cases if it had had these in contemplation” (Freeman, 2014:1572). In addition, where statutory law conflicts with the ECHR 1950, the judiciary can issue a written directive or make a “Declaration of Incompatibility” and pursue their own constitutional guidelines (De Smith, Woolf and Jowell, 1999:14). This possibility is enhanced by the European Court of Human Rights operating with a “margin of appreciation” to allow a degree of state autonomy in interpreting human rights standards (Freeman, 2011:123).

5.2 Case examples

This section examines two of the most high profile cases, those of Diane Pretty and Tony Nicklinson, who took their legal appeals for assistance to die to the Court of Appeal, the Supreme Court and the European Court of Human Rights. Review of their petitions explores how key human rights arguments have been invoked to challenge the current law and to extend the scope of existing rights in an end of life context. Prior to this, the case of Tony Bland, which pre-dates the HRA 1998, is outlined as significant in so far as this was the first time legality of the acts of killing and letting die were questioned and the issue of ending life was deliberated as an ethical dilemma in the courts.

5.2.1 Case of Tony Bland (1993)

Legal interest in the end of life debate was initiated by the landmark case of Tony Bland, a 17 year old male victim of the Hillsborough tragedy. Following his injuries, Tony Bland was in a persistent vegetative state. He had suffered brain stem death and was unable to move or communicate but was kept alive through artificial ventilation and nutrition. After a longer period with no prospect of recovery, his parents sought consent to withhold treatment and nutrition, and allow him to die (*Airedale NHS Trust v Bland* [1993]1 All ER 821 HL). A great deal of attention has been given to this benchmark case on the grounds that it this was the first

example in England and Wales to debate the circumstances under which a doctor can lawfully terminate life (Wicks, 2007). This case raised issues of best interests and was deliberated from the perspective of a patriarchal medical model of care that sought to preserve life, even against the wishes of the patient, which were expressed through the sentiments of his family. Although rights were not deliberated *explicitly* as such, the case of Tony Bland did *implicitly* suggest a right to respect individual dignity where there was no hope of recovery. By allowing Tony to die, his being subject to inhuman or degrading treatment would be limited.

In the case of *Bland*, all presiding judges defined artificial nutrition as medical treatment that could legally be (and subsequently was) withheld. They also deliberated the relationship between a doctor's duty of care and acts/ omissions, killing/ letting die and the doctrine of double effect. Lord Browne-Wilkinson argued in *Airedale NHS Trust v Bland* [1993] AC 789, at paragraph 885, "the doing of a positive act with the intention of ending life is and remains murder". Nonetheless, it was held that a doctor commits no offence when treating a patient in a way which hastens death, if the purpose of the treatment is to relieve pain and suffering (the so-called "double effect"). The House of Lords opinion was that no offence was involved in refusing or withdrawing medical treatment or assistance, ultimately because this involved an omission rather than a positive act, and held that it was lawful for doctors to discontinue treatment of a person who was in, what was then called, a persistent vegetative state (*Airedale NHS Trust v Bland* [1993] AC 789).

Delivering the judgement on *Airedale NHS Trust v Bland*, Lords Goff, Browne-Wilkinson and Mustill expressed concern about the artificiality of such a sharp legal distinction between acts and omissions in this context. They also saw the need for the law in this sensitive area to be clear. Interestingly, Lord Justice Hoffmann situated the debate in a social context. He attributed the complexity of the Tony Bland case as due to "[m]odern medicine...[it] faces us with fundamental and painful decisions about life and death which cannot be answered on the basis of normal everyday assumptions" (*Airedale NHS Trust v Bland* [1993] AC 789, paragraph 825). Advances in medical technology have influenced and shaped the late modern dying trajectory and this has led to some complex cases that challenge legal provision and expose the law as a blunt instrument.

5.2.2 Case of Diane Pretty (2001)

Diane Pretty suffered from motor neurone disease, an incurable, progressive and degenerative illness that rendered her physically incapacitated but did not affect her mental competence. This distressing condition “gradually destroyed her muscles, making it hard for her to communicate with her family. It left her in a wheelchair, catheterised and fed through a tube” (Dignity in Dying, 2013). Pretty wanted to end her life with the help of her husband before reaching the stage of, what she considered, unbearable suffering. She sought prior immunity from prosecution if her husband assisted in her death (*Pretty v DPP* [2001] UKHL 61). Diane Pretty grounded her motion on the basis of their marital status, her physical inability to end her own life due to disability, and the right to privacy in regard to her own decision-making ability on this matter. Pretty was the first individual to challenge the current legislation by suggesting that section 2 of the 1961 Suicide Act, if it prohibits this help and prevents the DPP undertaking not to prosecute if he does, is incompatible with the European Convention on Human Rights recently enshrined in UK law by the Human Rights Act 1998 (*Pretty v DPP* [2001] UKHL 61). Citing violation of the Convention rights soon after the HRA 1998 entered into force and petitioning an application for assistance to die positions the case of Diane Pretty as an important legal landmark.

The case of *Pretty* principally invoked respect for the right to self-determination at the end of life as a reflection of individual liberty and an attempt to maintain human dignity. Her appeal cited violation of the ECHR 1950 including: Article 2 the right to life; Article 3 prohibition of torture; Article 8 the right to respect for private and family life; Article 9 freedom of thought, conscience and religion, and Article 14 prohibition of discrimination.⁴⁸ The right to life is central to the debate on assisted dying. Its inviolable nature has been challenged in a number of ways. *Pretty*'s case began by questioning the inalienable status of the right to life and suggested that individuals who are suffering or dying, may rationally choose not to avail themselves of this rightful entitlement. Counsel for *Pretty* argued that Article 2 protects the *right to life* rather than life itself, and, on this basis, it is for the individual to choose whether or not to claim this right. In this way it was proposed that interpreting the scope of a right to life should include being able to waive the right to life.

⁴⁸ No violation was found of ECHR 1950 Art 14 and it was not discussed in depth. However, the case of *Pretty* could reasonably be argued on anti-discrimination grounds as she was physically unable to take her own life and on this basis requested the right to receive assistance. Not offering assistance to individuals who are physically unable to end their own lives impacts upon the rights of the disabled and in light of the increasing emphasis and prevalence of legal instruments that protect disability rights, such as the 2006 Convention on the Rights of Persons with Disabilities, this raises the question of why more appeals do not petition on this basis.

Especially in the face of unbearable suffering under medically hopeless conditions, it could be argued that individuals who may be aware the inevitable outcome is death should be able to waive their right to life in pursuit of their perception of a more dignified death. The case of *Pretty* highlights another of the difficult issues posed in the end of life debate on the boundaries of a right to life with regard to normative understandings and measuring quality of life. Despite its importance, the right to life is ambiguous in content. There is no widely accepted standard that measures life quality or defines a right to a decent quality of life. Life quality, which for many encompasses a notion of human dignity, can only be determined by the dying individual. Respect for this subjective assessment of life quality has implications that support human agency. Personal evaluations of life quality, within the lived experience, involves respect for individual liberty, even in circumstances where the person may choose not to act in what may appear to others to be in their best interests. One could argue that the right to life is incomplete if a rational person cannot decide to end their life on the basis that continuing to live would contravene their inherent dignity.

Counsel for *Pretty* challenged the juridical framework for end of life decision-making by suggesting a new concept, namely the *right not to live* as a conjunction of the right to life and the right to self-determination. A right not to live, in effect a right to die, would be applied in practice in the same manner that individuals may refuse life-saving or life-prolonging medical treatment, or may lawfully choose to commit suicide if they are physically able. *Pretty* argued further that the right to die is not the antithesis of the right to life but the corollary of it, and that the state has a positive obligation to protect both (*Pretty v DPP* [2001] UKHL 61). The Secretary of State replied with a number of objections to this interpretation of the right to life, which were upheld by the Court. He argued

The article protects the right to life and prevents the deliberate taking of life save in very narrowly defined circumstances. An article with that effect cannot be interpreted as conferring a right to die or to enlist the aid of another in bringing about one's own death (*Pretty v DPP* [2001] UKHL 61, paragraph 5).

This response was grounded in the sanctity of life and current legal enactment that prioritises protection of human life, but the response at this time illustrated a distinct lack of engagement with human rights and interest in debating the scope of rights that may be indicative of the unfamiliar nature of this initial case.

Article 3 of the ECHR 1950 confers respect for physical integrity and human dignity. It states “No one shall be subjected to torture or to inhuman or degrading treatment or punishment”.

The argument made by Diane Pretty for the right to die was grounded in the indignity and frustration of human suffering associated with not physically being able to end her own life and being refused assistance to do this. Counsel argued

In denying Mrs Pretty the opportunity to bring her suffering to an end the United Kingdom (by the Director) will subject her to the proscribed treatment. The state can spare Mrs Pretty the suffering which she will otherwise endure since, if the Director undertakes not to give his consent to prosecution, Mr Pretty will assist his wife to commit suicide and so she will be spared much suffering (*Pretty v DPP* [2001] UKHL 61, paragraph 11).

The chronic and debilitating nature of the dying process that characterised Ms Pretty's condition, prolonging the actual or anticipated undignified conditions under which Mrs Pretty must remain alive, could constitute inhuman or degrading treatment. Not allowing the option for assisted death may exacerbate suffering and result in an undignified and degrading experience. The appeal by Diane Pretty is significant in that it associates the phenomenon of suffering, traditionally grounded in a compassionate discourse, with human rights discourses through Article 3 where the relief or avoidance of unnecessary suffering as inhuman or degrading treatment is associated with a *dignified* death. Review of the literature in Chapter 2 suggested that, in a number of areas, a connection was evolving between understandings of human suffering and human rights. Classifying Ms Pretty's circumstances as a violation of Article 3 was, however, dismissed by Lord Bingham who decreed

An analogy might be found in the present case if a public official had forbidden the provision to Mrs Pretty of pain-killing or palliative drugs. But here the proscribed treatment is said to be the Director's refusal of proleptic immunity from prosecution to Mr Pretty if he commits a crime. By no legitimate process of interpretation can that refusal be held to fall within the negative prohibition of Article 3 (*Pretty v DPP* [2001] UKHL 61, paragraph 14).

Diane Pretty also cited ECHR, Art 8(1) the right to respect for private and family life, as a means to sanction an assisted death. This is a key argument in the debate but one that only appears to surface in relation to these individual appeals. A right to privacy highlights and protects individual liberty through sanctioning the right of individuals to self-determine their own actions within their private, family and home environment. Despite this, the right to privacy has been under-theorised both historically and philosophically and in relation to the end of life. Counsel for Pretty suggested extending the boundaries and context of this right to a private life to include a right to determine one's own death on the basis that

This right embraces a right to choose when and how to die so that suffering and indignity can be avoided. Section 2(1) of the 1961 Act interferes with this right of self-determination: it is therefore for the United Kingdom to show that the interference

meets the convention tests of legality, necessity, responsiveness to pressing social need and proportionality (*Pretty v DPP* [2001] UKHL 61, paragraph 17).

At the end of life, individuals prioritise their own values and beliefs, aspiring to die in a way that reflects these values. Curtailing certain actions by limiting privacy rights may challenge fundamental civil liberty and impact upon freedom to express personal values and beliefs. The right to privacy is categorised as a qualified right and interference with the enjoyment of this right is permissible only if the interference has a legal basis and is considered necessary in a democratic society to protect citizens from harm (ECHR 1950). Article 8(2) of the ECHR 1950 decrees that state interference in private life and circumstances permitting public authorities to intervene are only lawful when acting

...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.

The boundaries of privacy rights are particularly ambiguous and subject to interpretation. It is not always clear where and when legally valid expectations of privacy exist nor how they fare in relation to other legally recognised interests including public morality and national security. Privacy rights also vary depending upon the acceptability and nature of the social context. Any action, even if in private and between consenting adults, that results in serious harm or death as would occur in the case of assisting suicide are generally qualified under Article 8.

To further her claim to privacy rights, Counsel highlighted certain features of Mrs Pretty's case including; "her mental competence...her willingness to commit suicide if she were able... the absence of harm to anyone else, the absence of far-reaching implications if her application were granted" (*Pretty v DPP* [2001] UKHL 61). Citing violation of privacy rights which disallows rational human agency and limits individual liberty in determining one's own death issues a poignant challenge to a democratic government that has an obligation to respect the integrity of a dying person. Permitting the assisted death of a suffering person at the end of their life at their own reasonable request may confer, as *Pretty* suggests, minimal harm and implications for other members of society who must also be considered when legislating complex issues. However, at this time, the Secretary of State was quickly dismissive of the right to privacy as a basis for the right to die and claimed this informed living rather than dying. He also noted the conflicting nature of rights in relation to assisted death,

...the right to private life under Article 8 relates to the manner in which a person conducts his life, not the manner in which he departs from it. Any attempt to base a right to die on Article 8 founders on exactly the same objection as the attempt based on Article 2, namely, that the alleged right would extinguish the very benefit on which

it is supposedly based. Article 8 protects the physical, moral and psychological integrity of the individual, including rights over the individual's own body, but there is nothing to suggest that it confers a right to decide when or how to die (*Pretty v DPP* [2001] UKHL 61, paragraph 18).

Diane Pretty then applied to the European Court of Human Rights in 2002 where she was partially successful, in that it was held that her desire to end her life did engage Article 8.1 (Case of *Pretty v. United Kingdom* Application no. 2346/02). The European Court noted that member states enjoy a wide margin of appreciation on the issue of assisted dying and the concept of "private life" is a broad term not susceptible to exhaustive definition⁴⁹ (Case of *Pretty v. United Kingdom* Application no. 2346/02, paragraph 61). Disagreeing the opinion of the Secretary of State that private life refers to "the manner in which a person conducts his life" (*Pretty v DPP* [2001] UKHL 61 at para 18), the European Court observed

...that the ability to conduct one's life in a manner of one's own choosing may also include the opportunity to pursue activities perceived to be of a physically or morally harmful or dangerous nature for the individual concerned. The extent to which a State can use compulsory powers or the criminal law to protect people from the consequences of their chosen lifestyle has long been a topic of moral and jurisprudential discussion, the fact that the interference is often viewed as trespassing on the private and personal sphere adding to the vigour of the debate. However, even where the conduct poses a danger to health or, arguably, where it is of a life threatening nature, the case-law of the Convention institutions has regarded the State's imposition of compulsory or criminal measures as impinging on the private life of the applicant within the meaning of Article 8 § 1 and requiring justification in terms of the second paragraph (Case of *Pretty v. United Kingdom* Application no. 2346/02, paragraph 62).

Analysis of the *Pretty* judgement reveals the difficulty in deliberating human rights principles especially in hard cases that necessitate close scrutiny and a degree of interpretation. At the time of the *Pretty* case in 2001, the judiciary demonstrated an inexperience and reluctance towards exploring and appropriating the nature and boundaries of rights in an end of life context. When Ms Pretty's petition was heard at the European Court they found that Article 8.1 was engaged suggesting that the UK legislation on assisting suicide was not compliant with European human rights law. The case of *Pretty* suggests that attempts to expand human rights principles in relation to assisted death, are most persuasive through the right to privacy that

⁴⁹ In three subsequent decisions, the European Court has stated in clear terms that Article 8.1 encompasses the right to decide how and when to die, and in particular the right to avoid a distressing and undignified end to life provided that the decision is made freely (see *Haas v Switzerland* (2011) 53 EHRR 33, para 51, *Koch v Germany* (2013) 56 EHRR 6, paras 46 and 51, and *Gross v Switzerland* (2014) 58 EHRR 7, para 60).

promotes a sense of self. Autonomous individuals are demanding respect for decisions they make *in private* over their own bodily integrity.

5.2.3 Case of Tony Nicklinson (2012)

Reviewing the more recent case of Tony Nicklinson illustrates the extent to which rights discourses have developed within a legal environment and become more familiar terrain upon which to advance the case for a right to die. Tony Nicklinson suffered a stroke at the age of 51 years that left him completely paralysed. His case received in-depth coverage in national newspapers and television interviews (see BBC News, 2012, *The Guardian*, 16th September, 2012). In a statement from his first application for judicial review as it was heard at the High Court, he communicated with the aid of computer software to explain the nature of his suffering,

My life can be summed up as dull, miserable, demeaning, undignified and intolerable. ...it is misery created by the accumulation of lots of things which are minor in themselves but, taken together, ruin what's left of my life. Things like...constant dribbling; having to be hoisted everywhere; loss of independence...particularly toileting and washing, in fact all bodily functions (cited in *Nicklinson v Ministry of Justice* [2012] EWHC 2381).

Tony Nicklinson's petition contested the blanket nature of the prohibition of killing in the law of murder, in so far as it applies to cases of genuine consensual killing. His appeal was grounded in the right to privacy. Nicklinson applied to the High Court for a Declaration that it would be lawful for a doctor to kill him, or to assist him in terminating his life, and for a Declaration that the law, as currently drafted, was incompatible with his Convention rights under Article 8 (*Nicklinson v Ministry of Justice* [2012] EWHC 2381).

Nicklinson's case primarily cited respect for the right to privacy declaring a breach of Article 8 of the Convention. His application acknowledged that there was a risk of abuse in legalising assisted death but claimed this did not justify the government in failing to provide a solution (*Nicklinson v Ministry of Justice* [2012] EWHC 2381). In comparison to the earlier case of *Pretty*, who briefly argued that the right to a private and family life included a *right to choose* how and when to die (but was disregarded on the grounds that privacy rights did not relate to how a person ends their life), there was extensive deliberation over the boundaries and context of privacy. Rights discourses involving concepts of autonomy and dignity underpin the right to private life and these have been developed and foregrounded in the 2012 petition. Autonomy and dignity, grounded in human rights principles, are used to support the existing right to

privacy. The following argument highlights how central human rights discourses have become to the end of life debate,

...respect for human dignity is an integral part of the general legal tenets of Community law... This is a particularly important factor of the present case... Tony's stroke has condemned him to living in conditions in which he is deprived of all usual dignity and the law has deprived him of the right to say that enough is enough. For Tony, autonomy and dignity, humanity and justice require that he should be permitted to end his life; and it is submitted that Article 8 gives him the right to do so (*Nicklinson v Ministry of Justice* [2012] EWHC 2381, paragraph 88).

Counsel for Tony Nicklinson drew upon international human rights provision to challenge the lawfulness of the actions of the UK government. Similar to the observation discussed above by Keating (2016) that a new partial defence to murder is needed, Mr Nicklinson petitioned the court to "declare that the legislation under which murder carries a mandatory sentence of life imprisonment is incompatible with the European Convention in a case of genuinely compassionate voluntary active euthanasia" (*Nicklinson v Ministry of Justice* [2012] EWHC 2381, paragraph 22). Attempting to determine the issue under human rights law, Lord Justice Toulson argued in support of a new partial defence to murder through the defence of necessity. He stated

...whether or not Tony has what I will refer to as the right to die (using that expression as shorthand for a right not to be prevented by the state from undergoing voluntary euthanasia) under that article, the time has come when the common law should give respect to his autonomy and dignity by recognising that voluntary euthanasia can provide a defence to murder by way of the defence of necessity (*Nicklinson v Ministry of Justice* [2012] EWHC 2381, paragraph 50).

This comment illustrates firstly how the term "a right to die" has become a familiar expression within the legal arena and, secondly, demonstrates that judicial decision-making on the issue of assisting death has shifted and is now being debated under *human rights law* with respect for human rights principles in contrast to the *common law* which was utilised to determine the 1993 case of Tony Bland. The right to die is understood from the perspective of Lord Justice Toulson to have a basis in individual liberty whereby recognition and protection of personal autonomy and human dignity justify consideration when determining the common law position. Toulson, LJ, however, was in the minority as his arguments were dismissed by other members of the court on the basis that "current law does not recognise the 'best interests of the victim' as a justification or excuse for killing", although this statement ignored the example of withholding or withdrawing treatment within a medical context as discussed above. The judgement also failed to take account of "the compassionate motives of the 'mercy' killer"

claiming these motives “are in themselves never capable of providing a basis for a partial excuse” (*Nicklinson v Ministry of Justice* [2012] EWHC 2381).

After his legal petition failed, Tony Nicklinson as permitted under the Mental Capacity Act 2005, refused all food, water and medication, and he died of pneumonia on 22nd August, 2012. His case was taken up by his wife Jane who petitioned the Court of Appeal. This was dismissed on similar grounds to the 2012 application and for this reason is not analysed here ([2013] EWCA Civ 961). The case was then heard posthumously in the Supreme Court (*Nicklinson and another v Ministry of Justice* [2014] UK SC 38), where the appeal was underpinned by the values of liberty and dignity. It can be summarized as follows

The appellants’ case is that the Article 8 rights of Applicants should be accommodated by their being able to seek the assistance of third parties to enable them to kill themselves in a dignified and private manner, at a time of their choosing, in the United Kingdom, subject to some appropriate form of control so as to ensure that their decision to commit suicide is indeed voluntary, clear, settled and informed (*Nicklinson and another v Ministry of Justice* [2014] UK SC 38, paragraph 56).

In this most recent judgement, the right to privacy was once again discussed in great depth and reference was also made to other judgements in relation to section 2 of the Suicide Act 1961 being incompatible with Article 8 of the Convention. Despite respect for the apparent and unbearable suffering in the tragic case of Nicklinson, the principle justification advanced by Lord Reed for maintaining an absolute prohibition on assisting suicide was based on a utilitarian consideration. He argued there was a

...perceived risk to the lives of other, vulnerable individuals who might feel themselves a burden to their family, friends or society and might, if assisted suicide were permitted, be persuaded or convince themselves that they should undertake it, when they would not otherwise do so (*Nicklinson and another v Ministry of Justice* [2014] UK SC 38, paragraph 171).

The *Nicklinson* appeal was refused by a majority of seven to two, chiefly with due respect by the judiciary for the role of the law in democratic society to protect its citizens. Following this judgement, quite compellingly, three members of the Supreme Court indicated broad support for possible legal change, observing that the current law is becoming unfit for purpose. Once again, recommendations to Parliament were made pushing for legislation on this matter. President of the Supreme Court, Lord Neuberger, in his conclusion, implored Parliament to consider the human rights implications of the Suicide Act 1961 to avoid a future declaration of

incompatibility with ECHR 1950 Art 8, suggesting continuing with a blanket ban on assisted suicide was not justified as it amounted to an interference with privacy. Once the issue of assisted death is located in Article 8, as it is increasingly so, the burden of proof rests with the UK government to justify their decision to interfere with this right and prove that interference is proportionate. Lord Neuberger held that

...the arguments raised by the Secretary of State do not justify this Court ruling out the possibility that it could make a declaration of incompatibility in relation to section 2. The interference with Applicants' article 8 rights is grave, the arguments in favour of the current law are by no means overwhelming, the present official attitude to assisted suicide seems in practice to come close to tolerating it in certain situations, the appeal raises issues similar to those which the courts have determined under the common law, the rational connection between the aim and effect of section 2 is fairly weak...(*Nicklinson and another v Ministry of Justice* [2014] UK SC 38, paragraph 111).

The appeals of Diane Pretty and Tony Nicklinson are significant because they demonstrate how the use and development of human rights arguments in the end of life debate has shifted the issue from a purely medical dilemma into the legal and consequently political arena, where there is a potential for change in UK law and policy. The case of *Pretty* in 2001 invoked human rights principles and applied them to the issue of assisted death through the newly enshrined HRA 1998. Ms Pretty's case was pivotal in that it initiated deliberation on the boundaries of human rights arguing that concepts of rights were fluid, open to interpretation and could be appropriated in a new context, namely in relation to claims supporting an assisted death. Judicial response at this time was limited. Assisted death contravened current UK legal provision and there was little suggestion that the application of human rights principles could or should be deliberated in an end of life context.

The case of *Nicklinson* in 2012 interrogated the boundaries of human rights principles, particularly the right to privacy, in greater depth. At this time, rights arguments were gaining traction to the extent that they challenged government accountability suggesting that the state was acting disproportionately and UK law was incompatible with the human rights protected by the European Convention. The cases of *Tony Nicklinson* and *Diane Pretty* heard in High Court and their appeals to the European Court uncover division on two fundamental legal issues. First, that of appropriate legal response to assisting or encouraging a suicide and, second, the respective roles of Parliament, the domestic courts and the European Court of Human Rights in protecting and interpreting human rights. Despite compelling appeals by UK individuals requesting an assisted suicide through utilising existing human rights mechanisms

in the HRA 1998 and ECHR 1950, and an indication that rights arguments are an increasingly valid basis for the right to die, no cases to date have succeeded. However, the courts cite increasing discomfort with delivering judgements on the issue. The prevailing legal narrative is now being challenged through rights that protect the decision-making ability of competent individuals to determine their own death and the law needs more solid justification to maintain prohibition of assisted death.

5.3 Global perspectives

Rights-driven arguments have facilitated legal change in a number of other, primarily Western states. It is worth considering briefly this influence upon the legal status quo in the UK. Law and policy debates on end of life take place within a global frame of reference and on this basis, UK provision for the dying may be impacted by normative standards in other countries. This section introduces assisted dying in a global context to provide an indication of trends, then reviews the situation in the US state of Oregon and the Netherlands as examples of where legal provision for assisted dying is well-established.

At the time of writing, there was legal provision for assisted dying in the following European countries: Switzerland (1941); Holland (2002); Belgium (2002); Luxembourg (2008); and the American states of Oregon (1994), Washington (2009), Vermont (2013) and California (2015). Holland, Belgium and Luxembourg permit medically sanctioned voluntary euthanasia, while the Death with Dignity laws in Oregon, Washington, Vermont, and the End of Life Options Act 2015 in California allow mentally competent, terminally-ill adults to voluntarily request, and receive, a prescription for self-ingestion of lethal medication to hasten their death (Death with Dignity National Centre, 2014). The safeguarding criteria common to all countries where assisted death is legal, stipulate that requests must come from the patient themselves and in this way assisted death is underpinned by respect for the values of personal liberty and freedom of choice.

Most recently in February, 2015, the Canadian Supreme Court amended their Federal Criminal Code provision against assisted suicide which had been based upon a longstanding blanket prohibition (*Carter v. Canada (Attorney General)* [2015] SCC 5). Legal amendment that will be effected one year from this date states that physician assisted suicide is permitted if the “person affected clearly consents to the termination of life” and is considered to be suffering

from a grievous and irremediable medical condition. The Supreme Court in Canada justified this decision using the language of rights, which emphasised

An individual's response to a grievous and irremediable medical condition is a matter critical to their dignity and autonomy. The prohibition denies people in this situation the right to make decisions concerning their bodily integrity and medical care and thus trenches on their liberty. And by leaving them to endure intolerable suffering, it impinges on their security of the person. The prohibition on physician-assisted dying infringes the right to life, liberty and security of the person in a manner that is not in accordance with the principles of fundamental justice (*Carter v. Canada (Attorney General)* [2015] SCC 5).

Changes in global legislation on assisted death evidence a (primarily Western) shift in priorities at the end of life, which is increasingly grounded in human rights discourses involving respect for personal autonomy and human dignity. The above judgement also argues "intolerable suffering" as a valid reason to justify lifting the prohibition on assisted death that amounts to an impingement on personal "security".

5.3.1 Oregon

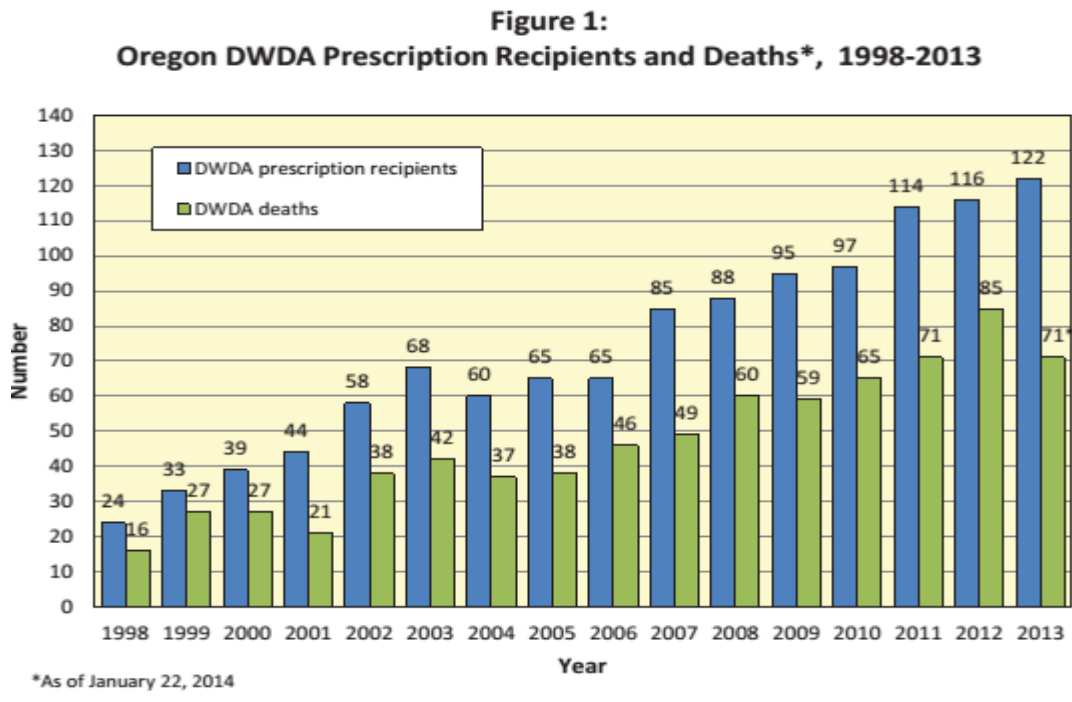
Voters first approved a change in the law on assisted dying in the US state of Oregon in 1994. The Oregon Death with Dignity Act (DWDA) entered into force in 1997 followed by effect in Washington, Vermont, and California (Death with Dignity National Centre, 2014). The US laws⁵⁰ specify that a person requesting assisted death must be at least 18 years old, a state resident, certified by two physicians as capable of making and communicating health care decisions for him/herself, and diagnosed with a terminal illness that is likely to lead to death within six months (Oregon DWDA, 2013). As part of the monitoring process, the Oregon Public Health Division is required by the DWDA 1994 to collect data and issue an annual report detailing the circumstances of deaths that were assisted. These statistics could help assess the potential implications of legalising assisted death in the UK. Statistics show that over a 10 year period the number of recipients of a prescription for lethal medication in the state of Oregon did increase from 68 in 2003 to 122 in 2013 suggesting that more people are requesting assisted death⁵¹ (Public Health Oregon 2014). However, the number of deaths from ingestion of the

⁵⁰ Interestingly, the DWDA 1994 states explicitly that assisted deaths in this manner *do not* "constitute suicide, assisted suicide, mercy killing or homicide".

⁵¹ For a comprehensive list of characteristics and motivations of the 752 patients who have died from ingesting lethal medication under the Oregon DWDA in the period 1998-2013: <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf> (Accessed 02.12.14).

lethal medication did not *correlatively* increase: 42 in 2003 compared to 71 in 2013 (Public Health Oregon 2014).

Figure 5.1 Oregon DWDA Prescription Recipients and Deaths 1998-2013 (Public Health Oregon 2014).



Notably, although 68 and 122 individuals received a prescription for lethal medication in the respective years 2003 and 2013 this figure did not equal the number of deaths. This indicates that death through the ingestion of barbiturates does not occur in a number of cases even though the medication has been prescribed. The Chair of the World Federation of Right to Die Societies, medical doctor Rob Jonquiere from the Netherlands, provided one explanation for this discrepancy during his guest address at a conference held by Friends at the End (FATE) in 2013. In his professional experience, not all patients who requested and received a prescription for lethal medication, chose to die by this method. He suggested “the knowledge that you have the choice may be more important than ingesting the choice” (Jonquiere, 2013). This resonates particularly in relation to clinical studies discussed in section 2.1.2 where it was highlighted how requests for assisted suicide were driven primarily by fear of dying and a desire to maintain individual liberty expressed as control over the process of dying.

5.3.2 The Netherlands

Dutch law is much broader in comparison, allowing both assisted suicide and voluntary euthanasia for individuals over the age of 16 without the criteria of mental competence. In the Netherlands, requests for assistance to die must be initiated by the patient or individual themselves, but mental capacity is not a pre-condition to permitting assisted death. Amendments currently proposed in the Netherlands include extending dying assistance to the elderly without a diagnosed terminal or serious illness (Jonquiere, 2013). Old age *per se* would not constitute a case for an assisted death, but the criteria of “completed life” combined with “minor age related illnesses” has been suggested by the Dutch NVVE.⁵² Dutch law specifies that the attending physician must, after consulting with another independent physician, comply with the due care criteria referred to in the Dutch Criminal Code art. 293, paragraph 2. This states the attending physician must be satisfied that the patient has made a voluntary and carefully considered request, that suffering was unbearable and that there was no prospect of improvement after having informed the patient about his situation and his prospects (Dutch Law, 2012). He must come to the conclusion together *with* the patient that there is no reasonable alternative in the light of the patient’s situation (Dutch Law, 2012). The use of *with* reflects personal autonomy in the decision-making process based on the earlier interpretation by Thorns (2013) rather than a notion of choice expressed as mere personal preference. International trends provide some indication that Western understandings of rights discourses are defining end of life provision and driving legal change. These findings are relevant considering the role and status of the UK in a global context. This motivates further examination of how, and to what extent, rights discourses could impact end of life law and policy in the UK.

5.4 End of life policy

High profile cases are important in that they can set legal precedent and provoke statutory changes. While the law typically defines normative standards in a democratic society, policy is also indicative of what is ethical and legally permissible at the end of life. Government healthcare policy strategically defines and shapes the delivery of services and care at the end of life through practical provision for the dying. The Department of Health (DOH) states that current policy provision is based upon “making sure people have the support, care and treatment they need, with the compassion, respect and dignity they deserve” (DOH, 2016). This section explores the centrality of human rights discourses apparent in government policy

⁵² NVVE provides information, consultation and education about euthanasia and assisted suicide in the Netherlands. This Amsterdam based organisation lobbies, supports and facilitates research and other initiatives related to the “self-chosen” death.

as it applies in England. The devolved administrations in Scotland, Wales and Northern Ireland are responsible for developing their own health policies. The NHS Constitution 2013, is discussed with reference to the Handbook to the NHS Constitution for England (2013), which explains and elaborates upon the rights and pledges in the policy. The *End of Life Care Strategy* was published by the Department of Health in July 2008 for England (similar strategies for the end of life have also been developed in Wales, Scotland and Northern Ireland) and was reported on annually. Advanced Care Planning including Advance Directives, and formation of the Dying Matters Coalition feature as part of, or derive from, *the End of Life Care Strategy* 2008 and for this reason are briefly included here.

5.4.1 NHS Constitution 2013

Before the start of each financial year, the Secretary of State prepares, lays before Parliament and publishes the Government's Mandate to NHS England according to guidelines for setting out the objectives and duties detailed in the NHS Act 2006 (*NHS England Framework Agreement*, 2014). The Department of Health works in partnership with NHS England to serve patients, the public and taxpayers. The policy formulated on end of life has implications for the UK government, which has a responsibility to discharge these duties effectively. The NHS Constitution for England dated 26th March, 2013 details patient "rights" and healthcare professionals' "duties" (NHS Constitution 2013). The NHS Constitution 2013 sets out the character of the NHS as a comprehensive and equitable health service. It claims to empower patients, staff and the public to know and exercise their rights in order to help drive improvements in quality, efficiency and responsiveness throughout the NHS (NHS Constitution (Handbook) 2013). It specifically states

The aim of the Constitution is to safeguard the enduring principles and values of the NHS. The Constitution also sets out clear expectations about the behaviours of both staff and patients. It is intended to empower the public, patients and staff by setting out existing legal rights and pledges in one place and in clear and simple language. By knowing and exercising their rights, the public, patients (their carers and families) and staff can help the NHS improve the care it provides (NHS Constitution (Handbook) 2013:3).

The aims of the NHS Constitution are largely grounded in these "legal rights" where it is claimed that through "knowing and exercising" these rights, individuals can improve the quality of care that the NHS provides. This illustrates how central human rights discourses have become in developing and defining quality end of life care and suggests that this language has the potential not only to influence options at the end of life, but also the direction of the NHS.

The NHS Constitution Handbook 2013 offers a novel differentiation between rights defined as “legal entitlement protected in law” and “pledges”. The concept of rights as legal entitlements, supports a legal positivist perspective, while “pledges” are more aspirational. These pledges were considered “not legally binding and cannot be guaranteed for everyone all of the time, because they express an ambition to improve, going above and beyond legal rights” (NHS Constitution (Handbook) 2013:4). This lack of clarity and understanding on the nature and content of rights is broadly indicative of government end of life policy. The list of rights documented under section 3a on page 6 of the NHS Constitution 2013 are a peculiar amalgam of rights, collectively termed “legal rights” which include, among others, the right to access NHS services free of charge and the right not to be subject to unlawful discrimination. The Handbook, in each case, refers to the source of the stated rights and these are, for the most part, grounded in statutory provision. In the case of free NHS services, the source cited is the NHS Act 2006, section 1 which sets out the primary duty of the Secretary of State to promote a comprehensive health service and to exercise the Secretary of State’s functions as to secure the services for that purpose. The right not to be discriminated against is protected by provisions in the Equality Act 2010. Other rights, including access to appropriate healthcare, are also grounded in the NHS Act 2006, while the right to nationally approved treatments, drugs, and programmes falls under the remit of NICE, and the right to vaccinations is provided through the Joint Committee on Vaccination and Immunisation (NHS Constitution, 2013:7).

Following this rather miscellaneous assortment of rights, the NHS Constitution subsequently attempts to differentiate between the idea of legal rights and human rights locating the source of *human* rights in international mechanisms (although these are poorly referenced as such). Section 3a of the NHS Constitution (2013:8) claims “the right to be treated with dignity and respect in accordance with your human rights”. The Handbook to the NHS Constitution 2013 acknowledges the broad and relative scope for interpretation of dignity and respect but, in contrast to other rights protected in the Constitution, it relates these to international mechanisms. In this way, the policy discourse attempts to validate concepts of dignity and respect for privacy through association with the human rights recognised in the ECHR 1950 suggesting, “the right to dignity includes a right not to be subjected to inhuman or degrading treatment. The right to respect includes the right to respect for private and family life” (NHS Constitution (Handbook) 2013:53). The source of the right to be treated with dignity and respect, including respect for private and family life, is stated as derived from the rights conferred by the ECHR 1950. These rights are protected by Articles 3 and 8 but are not referenced as Article 3: the right not to be subject to inhuman or degrading treatment or

Article 8: the right to respect for private and family life. It is noted however, in the same section, that these rights are given effect in UK law by the Human Rights Act 1998, correctly highlighting that it is unlawful for a public body to act incompatibly with those ECHR rights according to section 6 of the Human Rights Act (NHS Constitution (Handbook) 2013:53).

5.4.2 End of Life Care Strategy 2008

The foundations and aims of the strategy are explained by the following statement,

In the past, the profile of end of life care within the NHS and social services has been relatively low. Reflecting this, the quality of care delivered has been very variable. The aim of this strategy is to bring about a steep change in access to high quality care for all people approaching the end of life. This should be irrespective of age, gender, ethnicity, religious belief, disability, sexual orientation, diagnosis or socioeconomic status. High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere. Implementation of this strategy should enhance choice, quality, equality and value for money (End of Life Care Strategy 2008:33).

The objectives of the End of Life Care Strategy 2008,⁵³ in contrast to the NHS Constitution 2013 do not explicitly discuss rights. However, an understanding of rights is evident through the aim to enhance dignity for the dying person based upon personal choice, respect for human beings and access to high quality care. The intention behind this policy appears to permit individuals “more choice” and “enhance choice” but, despite an implied right to choose, there are still limits that are determined by the current law. Provisions that support patient decision-making in this policy includes a Preferred Priorities for Care (PPC) document that individuals hold themselves and take with them if they receive care in different places. It records individual thoughts about personal care and future choices at the end of life including a “Preferred Place to Die” option⁵⁴ (End of Life Care Strategy 2008:54). Information about choices, and who might be involved in their care or present at their death can also be noted, enabling care staff to be aware of individual preferences, thereby ensuring continuity of care (End of Life Care Strategy 2008:54).

⁵³ This strategy has now been replaced by a document drawn up by the Leadership Alliance for the Care of Dying People (LACDP), titled *One chance to get it right*. It details five new Priorities of Care for setting out standards of care for the dying in 2014-2016 (NHS England, 2014). Interestingly, this document focuses on the “wishes” and “preferences” of the dying person and although it details “duties” and “responsibilities” of healthcare professionals, there is no explicit mention of rights.

⁵⁴ Despite this option to die at home, a survey conducted by the Royal College of Nursing involving 7,700 community palliative care nurses in 2014 reported 7/10 nurses had witnessed dying patients being admitted to hospital due to insufficient resources for them to die at home. Only 36% of community nurses declared they had team resources available to deliver 24 hour care at home (Royal College of Nursing, 2014).

One of the key areas addressed in the End of Life Care Strategy 2008 was that

At a national level, the Department of Health will work with the National Council for Palliative Care to develop a national coalition to raise the profile of end of life care and to change attitudes to death and dying in society (End of Life Care Strategy, 2008:11).

This coalition was named Dying Matters. They have a detailed and comprehensive website and their community outreach programmes and organized events encourage openness in speaking about dying in the public sphere. Examining their website, www.dyingmatters.org, the dominant rhetoric is that of personal choice and autonomy in the decision-making process at the end of life. But, as with the End of Life Care Strategy 2008, there is no explicit use of the term “rights”. Although Dying Matters emphasise respect for individual autonomy, it is clearly stated that they have no official position in relation to euthanasia or assisted dying (Dying Matters, 2015). This clause may be necessary to ensure there is no direct conflict of interest with the law as it stands.

In contrast to statutory law, the scope for a right to die is substantially enhanced by Government policy on health and end of life care that promotes patients’ rights through an emphasis on personal choice and human dignity. Both the NHS Constitution 2013 and the Department of Health End of Life Care Strategy 2008 refer to the rights of individuals who are considered mentally competent by the Mental Capacity Act 2005 to request, withdraw from or refuse potentially life sustaining treatment. These policies are supported by guidelines from the General Medical Council (GMC), which also sanctions mentally competent adults being able to communicate an intention to end their own life through their right to refuse medical and surgical treatment. This includes refusing life-sustaining treatment such as intubation for ventilation purposes or amputation to avoid sepsis (GMC *a*, 2014). Patients who do not wish to, or are unable to, feed themselves or ingest food and water due to illness or incapacity also have the right to refuse help with this or artificial nutrition and hydration at any stage of their illness (GMC*a*, 2014). These rights enable and protect autonomous decision-making in the dying process, but are limited in that the individual must have certified mental capacity and not require outside assistance. There is then to this extent, already a presumptive right to die through the right to refuse nutrition, medical aid and life-sustaining treatments or to end one’s own life. However, this does not extend to being able to request death involving assistance from a third party.

To reflect individual choice, Advance Directives or Advance Decisions, formerly known as Living Wills are referenced in both the Department of Health End of Life Care Strategy 2008 and the

NHS Constitution 2013. This is a statement in which mentally competent adults can pre-record their individual wishes in the event of future serious illness or disability based on their own values and beliefs. Advance Directives mirror legal and medical guidelines in that they allow refusal of medical intervention such as cardiopulmonary resuscitation or discontinuance of treatment, including antibiotics and artificial nutrition or hydration, but they do not permit individuals to request assistance to die. Advance Directives do not have to be drawn up by a solicitor. The forms are freely available online or can be downloaded from the National End of Life Care Programme or Compassion in Dying (a sister organisation to Dignity in Dying). This document does, however, need to be signed, dated and witnessed in order for it to be recognized as a legal document. Individuals are advised to inform their families, general practitioners and healthcare professionals if they have an Advance Directive, but there is currently no national electronic database or visible method of recording and making clear whether a person has filled out an Advance Directive. Medical professionals would have to be aware that this provision exists before they could act upon it. Advance Directives are generally considered binding in England and Wales, but the force of their legal status is open to interpretation under section 25 of the Mental Capacity Act 2005. This clause states that Advance Directives are not applicable if circumstances change in a way that the patient could not have foreseen (Mental Capacity Act, 2005, s25). Given the varied and imprecise trajectory of illness, and medical uncertainty especially during long term ill-health and unforeseen complications, an Advance Directive that respects individual choices may not be legally valid.

Conclusion

This chapter has examined where, and how, rights discourses have been articulated at the end of life in UK law and policy documents and included a brief overview of assisted death in a global context. Legal provision regarding assisting death includes the Homicide Act 1957 and Suicide Act 1961. These legal instruments have remained constant to date as has the Criminal Justice Act 1967, which has relevance for the role of doctors in permitting the ending of life at their own medical discretion where actions taken are deemed to be in the patients' best interests. Analysis of the current law has highlighted areas of inadequacy that are ambiguous in relation to the end of life: the questionable ability to apply discretion in hard cases; the differentiation between killing and letting die, and the lack of partial defence to murder. In 2010, the DPP published his *Policy for Prosecutors in Cases of Encouraging or Assisting Suicide* following the 2009 appeal of Debbie Purdy to clarify the circumstances under which criminal

prosecution for assisting suicide was more or less likely. Although not incompatible with the Suicide Act 1961, this policy, in effect, sanctions assisting suicide as a compassionate response.

The findings of this chapter suggest the HRA 1998 has been influential in transforming the issue of requested death from an ethical dilemma, initiated by changes in the dying trajectory and perpetuated by advances in medical technology, to a human rights dilemma where rights arguments are now being invoked in individual petitions to courts of appeal. The limitations of statutory law are increasingly confronted by claims articulated through human rights principles and a rising human rights rhetoric that has been applied to challenge the boundaries of existing rights and interrogate legal authority in governing end of life decisions. The historic case of Tony Bland raised the end of life as an ethical dilemma in the courts, challenging the law to clarify their position on withdrawing treatment and letting die. In the period since, the cases of Diane Pretty and Tony Nicklinson, as high profile examples, have used rights that emphasise personal liberty, respect for privacy and human dignity as the basis for advancing their arguments for assisted death. Both of these recent legal petitions put forward arguments that are supported by the provisions in the HRA 1998.

In practice, legalisation of assisted suicide in the UK would necessitate statutory amendments to both the Suicide Act 1961 and the Homicide Act 1957 either to decriminalise the act of assisting a suicide or, as suggested above, to introduce a new partial defence to the crime of murder. As the scope of existing legal rights is interrogated, some discrepancy with current UK law arises. In 2002, when the case of *Pretty* proceeded to the European Court, it was ruled that Article 8: the right to respect for private and family life *was* engaged suggesting that the UK legislation on assisting suicide was not compliant with European human rights law. Analysis of the above cases founded on violation of established legal rights, indicates that the nature and understanding of human rights principles are open to further deliberation and interpretation. An alternative route to legalise assisted death is possible if the judiciary stress the incompatibility of the law and ECHR obligations sufficiently forcefully for Parliament to debate and introduce a new law.

Human rights discourses are used prominently in healthcare policy that defines end of life standards of care and healthcare professionals' duties in England. Analysis of Government end of life policy through the NHS Constitution 2013 and End of Life Care Strategy 2008 revealed

that rights discourses grounded in individual liberty dominate current provision. This is evidenced through emphasising the values of choice and dignity in end of life decision-making which resonate with popular, accessible and contemporary public discourses. Choice is provided in some aspects of end of life care, expressed loosely as a “right to choose,” including preference over place and who is present at time of death, plus the ability to refuse medical treatment that knowingly will lead to death. Ultimately, this right to choose articulated in end of life policy is not legally binding and specifically does not extend to requesting assistance to die, even when the request is rational and persistent, or generated by a state of unbearable suffering.

An incompatibility with policy discourse, supplemented by consumerist demand, reveals an area of emerging dissatisfaction upon which the current law is being challenged. Individual legal petitions have shifted the onus of responsibility upon the Government to defend their prohibition on assisted dying or risk the European Court issuing a declaration of incompatibility. The Supreme Court has urged Parliament to consider the issue as a matter of urgency. These factors suggest that in a contemporary social context, and driven by the rising persuasion of rights arguments, statutory amendment may be necessary, if not imminent.

The House of Lords, as a major UK political institution, has the potential to influence legislation on the issue and assisted death has been debated in this forum on a number of occasions. Members of the Lords have time and experience to scrutinise proposed Bills to change the law on assisted dying and examine the ethical and practical implications of a legalised right to assisted death. In this way they can provide a well-informed analysis of issues in the debate. The following chapter examines in-depth particular aspects of the dilemma as they emerge through the historical and contemporary House of Lords debates to explore the prevalence and development of rights discourses in an end of life context.

CHAPTER 6

Historical and contemporary debates in the House of Lords

The role of the House of Lords is to deliberate government legislation which includes the possibility of drafting or amending Parliamentary Bills. There is a range of political allegiances in the House of Lords. Figures in 2016 reveal 255 Conservative Members, 209 Labour, 105 Liberal Democrats and 177 Crossbenchers plus 26 Bishops (House of Lords 2016). These eligible Lords may “scrutinise bills, investigate government activity through committee work, and question government through oral questions and debates” (House of Lords 2016). Analysis of the discourses used by Members as they advance their arguments for or against the legalisation of assisted dying was selected for this research on the basis that the Lords are part of a major UK political institution and have the time, professional experience and inclination to debate complex issues in-depth, “giving intense and detailed attention to the minutiae of legislation so as to test its real scope and consequences” (House of Lords, 2003 col 1233). Their competence was praised by Lord Haskel commenting on the role of the House of Lords in comparison to the House of Commons,

We consider Bills in detail. Generally we have more time and we often have more relevant experience-and, yes we are less politicised-whereas in the other place, sometimes large chunks of legislation are not even considered in the Committee (House of Lords, 2014 col 891).

The purpose of this chapter is to explore the centrality of human rights discourses through the historical and contemporary debates on assisted dying. It examines the ways in which members of the House of Lords articulated their views and overall positions on end of life and the ways in which conceptions of rights featured in advancing both sides of the argument throughout the debates. This chapter is divided into three sections that focus on the Bills and ensuing debates from 1936, 2003 and 2014 in chronological order. By way of introduction, an outline of the Bills and main features of each debate are provided in the table below.

Figure 6.1 Overview of the 1936, 2003, and 2014 House of Lords Bills and debates

Year	1936	2003	2014
<i>Bill proposal</i>	“To enable persons suffering from incurable, fatal and painful disease to receive Euthanasia under certain conditions”	“To enable a competent adult who is suffering unbearably as a result of a terminal or a serious and progressive physical illness to receive medical help to die at his own considered and persistent request”	“To enable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life”
<i>Debate focus</i>	Compassionate (medical) response versus sanctity of life	Individual liberty rights versus state responsibility to protect the vulnerable	Rights arguments used explicitly and implicitly on both sides of the debate
<i>Serves to advance</i>	Ethical debate on euthanasia as a political issue	Arguments for self-determination in an end of life context	Deliberation of human rights principles and power of rights discourses at end of life
<i>Outcome</i>	Majority of 35 against, 14 in favour	Majority of 148 against, 100 in favour. Bill proceeded to Second Reading but ran out of time at this stage	Numbers equally divided at Second Reading, unanimous move to proceed to Committee Stage but the Bill ran out of time at this stage

The first part of this chapter presents the initial Voluntary Euthanasia (Legalisation) Bill 1936 and explores the subsequent debate to illustrate the historical context and language used to

express arguments at this time. The later House of Lords Bills and debates from 2003 and 2014, are addressed in sections 6.2 and 6.3 respectively. Each of the sections provide an overview of the Bill before outlining the debates and raising any arguments that are especially prominent or differ greatly from other debates. Specific issues in the debates are then discussed in detail.

6.1 Voluntary Euthanasia (Legalisation) Bill 1936

Lord Ponsonby first introduced a Bill for debate in the House of Lords on voluntary euthanasia in 1936 with the support of The Voluntary Euthanasia (Legalisation) Society (VES).⁵⁵ The Voluntary Euthanasia (Legalisation) Bill 1936 proposed “[T]o enable persons⁵⁶ suffering from incurable, fatal and painful disease to receive Euthanasia under certain conditions”. Prior to the timetabled Voluntary Euthanasia (Legalisation) Bill 1936, Killick Millard delivered his 1931 Presidential Address to the Society of Medical Officers for Health on the topic of Euthanasia. He observed that

In spite of all the advances which preventive and curative medicine have made and all that modern science has achieved in the alleviation of human suffering, the fact remains that vast numbers of human beings are doomed to end their earthly existence by a lingering, painful and often agonising form of death (Millard, 1931:11).

The motivation behind this first Bill was primarily a *compassionate* response to alleviate the suffering of incurables. It was prompted by these arguments of Killick Millard. The wording of the Bill invoked the notion of a fundamental *right* to decide one’s own end but analysis of the subsequent 1936 Parliamentary debate reveals very limited mention of rights or references to concepts of rights.

The procedure for requesting euthanasia was clarified in section 3(1),

The person desiring to receive euthanasia shall make an application...stating that he is suffering from an incurable, fatal and painful disease; that his near relatives have been informed; that his affairs are in order; that he desires to anticipate death by euthanasia and that he knows of no valid reason why a permit should not be granted (Voluntary Euthanasia (Legalisation) Bill 1936).

This application, supported by two independent medical certificates, was intended to be heard in a Court of Summary Jurisdiction where, if satisfied, the court would issue a permit to the

⁵⁵This was launched in December 1935 by Dr Charles Killick Millard, Medical Officer for Health.

⁵⁶ Persons eligible are adults over the age of 21 years. Later Bills make provision for adults as those over 18 years, reflecting other legislation that recognises a lowering of age for capacity in decision-making on personal issues.

applicant and the medical practitioner who must hold a license to euthanise. Although this Bill is historically the first of its kind that permits a doctor to legally end the life of a dying person at their request, involvement with independent assessors demonstrates well considered safeguards. This is the only Bill that proposes to use the law courts to assess requests for assisted death. This option is not discussed in later Bills and only surfaces once in the 2014 debate, briefly mentioned in the contribution from Lord Carlisle.

6.1.1 The 1936 debate

In 1936, the main body of the debate centred upon the value of compassion in the face of unbearable human suffering. Members of the Lords who supported the legalisation of assisted death in this debate drew upon a compassionate discourse that focused on the relief of suffering associated with dying from an incurable or serious illness as their primary motivation for a change in law. Typical contributions in this debate summarised assisted death as “to substitute for a slow and painful death, a quick and painless one” (col 475) and “an easy release for the dying” (col 499). Early arguments for the legalisation of assisted death were typified by a compassionate discourse grounded in the desire to spare painful “incurables” further or unnecessary suffering. This is a different approach to that of rights, and one that was historically specific.

Assisted death argued as a merciful act was contested by religious-based arguments citing the sanctity of human life as of value in itself and important to the attending doctor, duty-bound to preserve life. The Archbishop of Canterbury emphasised any taking of human life as contrary to a natural law approach that regards God as sovereign over matters of life and death. He located the moral aspects of the debate within wider society, concerned that if the law permitted man to end a life no longer deemed valuable it would place additional responsibility on the person to determine when they cease to exist as a valuable individual (col 487). These views are reflective of Christian teaching and a closer adherence to a religious framework at this time, demonstrating great respect for the authority of the Church on matters of life and death. One contribution expressed emphatic opposition to the Bill beyond religion

...it is not opposed only on Christian and moral grounds, it is opposed because it is contrary to the law of nature. We do not oppose it because the Church condemns it but because the law of nature brands it as evil and a cowardly act (col 479).

In contrast, some of the Lords at this time supported proposals to legalise assisted death despite their religious convictions. They argued that this support did not diminish their respect for the sanctity of life. This argument was revealed as common to all debates where religious members justify their support for assisted death on a compassionate basis in order to relieve unbearable or protracted suffering. In 1936, these contributions chiefly stated that the pity and compassion driving the Bill was in harmony with Christian tradition. The Earl of Listowel in support of the Bill concisely argued

...the cardinal point of Christian ethic has been the exercise of charity. Any Bill that would extend this principle of charity, of pity and compassion is surely one that is in harmony with the main body of the Christian tradition (col 501).

The 1936 Bill did acknowledge the responsibility of “[t]he person desiring to receive euthanasia” in making the initial application and this suggested a notion of individuals acting with agency and on the basis of their own rational free will. However, concepts of individual liberty, personal autonomy and human dignity to determine end of life decision-making were not discussed explicitly in the debate. Reflecting the social context at this time, the relationship between the doctor and incurable patient was typically authoritarian. The patient was subject to medical authority and a passive recipient of the wisdom of the attending doctor. There was only a singular reference to a conception of personal liberty in support of progress where it was suggested that

[r]esulting from our natural habit of freedom of thought and discussion, considerable changes in standards of conduct, in the evaluation of morals and manners will evolve without prior or corresponding alterations in legal Statutes. I say this is all to the good (col 472).

Taking into consideration that this debate was on a much smaller scale than later debates, (the transcript only spanned 50 columns) two comments directly made reference to rights. These contributions demonstrated some evidence of a traditional assumption of individual rights as legal entitlements. Proponents of the 1936 Bill articulated their aims from a legal positivist perspective on rights. The “right to demand” state assistance to die was justified through a compassionate and just desire to relieve suffering in the case of serious, incurable illness. This contribution sought

...to obtain legal recognition for the principle that in case of advanced and inevitably fatal disease, attended by agony which reaches, or oversteps the boundaries of human endurance, the sufferer, after legal inquiry and after due observance of all safeguards, shall have the right to demand and be entitled to receive release (col 468).

There was no further elaboration or comment upon this articulation of rights suggesting that at this time the Lords were not familiar with rights discourses, or applying an understanding of rights, to debate complex ethical issues. The legalisation of voluntary euthanasia was also a new topic for debate.

The second comment on rights was from the Lord Archbishop of Canterbury who expressed his concern that legal change may reduce the value accorded to all human life and encourage other individuals than those who are dying, to request a right to die,

...if this Bill passed might a man not say: "The law has now expressly recognised that if a man finds the continuance of life intolerable and of no sort of value to him he may take steps to bring it to an end. I find that this shame or this sorrow which has come to me would make my life henceforth intolerable, deprive it of any sense of value, and therefore I claim the right to bring it to an end?" (col 487).

This comment demonstrated respect for the law as an indicator of moral and normative standards. It also adopted a position on rights as legal claims, a perspective that is also identified through the arguments in the later debates.

Critical summary

With the exception of the two contributions above, the 1936 debate did not invoke *rights* discourses. Assisted death was grounded in *compassion*, and the relief of suffering regarded as an act of mercy. Opposition to the legalisation of assisting death was primarily from a religious perspective and a notion that the duty of doctors was to "cure not kill". However, it was also shaped by the social context. At this time, the act or intention to commit suicide was illegal and had traditionally been associated with states of insanity or depravity. On this basis, suicides were denied a Church of England burial and their life insurance policy was declared void (Voluntary Euthanasia (Legalisation) Bill 1936). This historic debate was the first time that assisting in the suicide or death of another, albeit incurable individuals, had arisen as a topic on the political agenda.

Early in the 1936 debate, Lord Ponsonby suggested motivation for requesting an assisted death may be propagated by

...the consciousness of being a burden, the despairing view that you yourself are no longer of any use, the prolonged anxiety of others of which the patient is aware,[this] may be as poignant as the suffering itself (col 469).

Ending life at a person's own request as a well-contemplated, rational response to a state of incapacity or suffering based on a desire to relieve the burden of care on others was received at this time as a peculiar and original idea. The Suicide Act 1961 has since decriminalised the act of suicide, and this, in conjunction with social and cultural changes, has impacted attitudes towards dying so that attitudes and the discourses with which these attitudes are expressed, have shifted to define arguments differently in the more recent debates.

Following defeat of the Voluntary Euthanasia (Legalisation) Bill in 1936, the issue remained dormant on the political agenda. The Great British Government were occupied with the war in Europe and, in the post Second World War (WWII) period of austerity, their efforts were channelled into rebuilding the social and economic infrastructure and developing the welfare state. Voluntary euthanasia surfaced as an issue for debate in 1950, but the Bill was withdrawn before dividing the House. The 1950s were not a decade for moral reform, but after the Suicide Act was amended in 1961 and the law relaxed in regard to other personal liberties, including decriminalising homosexuality and permitting abortion in 1967, a new Bill was introduced to extend the remit of the Suicide Act 1961. This Voluntary Euthanasia Bill and debate in 1967 was unsuccessful. It largely centred upon medical practice and ethical arguments rather than rights discourses, and for this reason was not selected for analysis.

6.2 Patient (Assisted Dying) Bill 2003

The 2003 Patient (Assisted Dying) Bill was proposed as a Private Members Bill by Lord Joel Joffe, a former human rights lawyer and Labour peer. The Bill endeavoured to

Enable a competent adult who is suffering unbearably as a result of a terminal or a serious and progressive physical illness to receive medical help to die at his own considered and persistent request (Patient (Assisted Dying) Bill 2003).

These intentions mirror the 1936 Bill whereby medical help in one form or another is provided to end the life of a seriously ill person at their own request. Proposing similar criteria, the request for assisted death must be made by an individual who is incurable and suffering from, what is termed in this Bill, as an "irremediable condition" to include "a terminal or a serious physical illness" (Patient (Assisted Dying) Bill 2003). This Bill, in common with the 1936 Bill specifically sanctioned voluntary euthanasia under section 1(2) where it defined "'assisted dying' means the attending physician, at the patient's request either providing the patient with the means to end his life, *or ending the patient's life*" [italics added] (Patient (Assisted Dying) Bill 2003).

This Bill also specified safeguarding procedures for requesting assisted death to include a written declaration witnessed by a solicitor and non-family member, who shall not inherit the person's estate (Patient (Assisted Dying) Bill, section 3, 2003). All Bills support the requirement of mental competence in order to make an "informed decision" at the end of life. However, this is the only Bill that has highlighted the need to establish a monitoring commission. In the 2003 Bill, the components of an informed decision were defined. These included time to reflect and reach carefully considered choices based on interaction with "the attending physician" and sharing of information. Although the choices available were still defined within a medical model of care, this indicated the emergence of a concept of personal liberty with the dying person making an autonomous decision on the end of life rather than making choices based solely on preference. It was necessarily

...based on an appreciation of the relevant facts and after being fully informed by the attending physician of (a) his medical diagnosis; (b) his prognosis; (c) the process and probable consequences of being allowed assistance to die; (d) the alternatives, including but not limited to, palliative care, care in a hospice and the control of pain (section 1(2) Patient (Assisted Dying) Bill 2003).

6.2.1 The 2003 debate

The wording of the 1936 and 2003 Bills is not too dissimilar. They were motivated by the same intentions, but analysis of the debates reveals a very different picture. Historically, the concept of individual liberty, and dignity understood from a human rights perspective, did not feature in an end of life context. The timing of death was determined by a sovereign God subject to nature or the dictates of the medical profession which determined the best interests of the patient. By 2003, the terms of the debate had demonstrably shifted and the issue of assisted death was developing from a medicalised dilemma that balanced compassion with the role of doctors, to a politicised dilemma. This politicised perspective was defined through concepts of rights articulated implicitly and, on occasion, explicitly to advance arguments for self-determination in an end of life context. In the 2003 debate, arguments in support of a right to die prioritised autonomous decision-making, citing respect for individual liberty rights, not only in life, but also in death. However, this was weighed against the responsibility of the state to protect the rights of wider society. In this section, key arguments both for and against assisted death in the 2003 debate are discussed. The prevalence of arguments that invoke rights discourses intentionally, or otherwise, is greatly increased compared to the minimal incidence in 1936 suggesting that this was the terrain upon which the issue was beginning to be debated.

Liberty

Lord Joffe introduced this Bill for debate by foregrounding a conception of individual liberty as a basis to determine the timing of death. He argued

The Bill seeks to achieve that purpose by changing the law so as to add to the freedom that patients already have to commit suicide or to refuse medical treatment which could save their lives, the freedom to ask a doctor to bring their suffering to an end by assisting them to die at a time of their choosing (col 1586).

Lord Joffe's attempt to expand the remit of fundamental freedoms was closely aligned with the current provision in law and healthcare policy that permits suicide and allows refusal of treatment or medical intervention by rational adults. This tactical move highlighted that law and policy already respects personal freedoms suggesting that the proposals in this Bill would only serve to extend the existing provision.

Lord Joffe, as a former human rights lawyer, used familiar language when he summarised the case for a change in law as "based on personal autonomy-the right of each individual to decide for himself or herself how best he or she should lead their lives" (col 1587). In the 2003 debate, an understanding of human rights underpinned by a concept of individual liberty starts to emerge. A fundamental right for individuals to decide matters of life and death in accordance with their bodily integrity is reflective of a natural law position on rights that grounds an inherent notion of human freedom. This is illustrated by way of the contribution from Baroness Jay, "issues of human rights and the role of individual autonomy in making decisions is fundamental. My view today is that the individual human right to choose should be paramount" (col 1604). The importance of individual liberty in regard to establishing human rights is emphasised. The "right to choose", however, is not a legally recognised term. Instead it is derived from contemporary interpretations of individual liberty that promote human agency and in an end of life context, the right to choose is applied to making decisions that reflect one's own values and convictions.

Lord Gray (col 1649) acknowledged the constructed nature of a right to choose "[t]he right to choose" is an expression used loosely in many campaigns, but surely the right to choose to end the suffering caused by terminal illness is the greatest of all rights". This argument initially appeared derogatory and less valued on the basis that a right to choose was utilised solely for the purposes of campaign rhetoric, and only "loosely" at that. However, his support for a right to choose was lent gravitas by emphasising the potential suffering and finality of the dying

process. The enormity and distress of suffering in dying elevated the importance of personal choice to “the greatest of all rights”.

An understanding of rights grounded in personal liberty was at the forefront of arguments that supported legalising an assisted death. However, not all members prioritised, or accepted, a concept of personal liberty or the possibility of extending the boundaries of existing liberty rights to determine the dying process. Typical contributions that articulated this sentiment, and in doing so used an understanding of rights to negate or dispute assisted death, included the following:

...autonomy is one of the buzz words of the pro-euthanasia lobby...[H]owever, autonomy is not an absolute right that each of us, as individuals can exercise while living in our own little bubbles (col 1617).

I do not doubt that personal autonomy is a moral good, but that it is not the only determinant of what constitutes our human meaning and purpose. My human meaning and purpose consists not only in exercising individual choice-but like all human beings I have to do that in a social context (col 1652).

Autonomy is not an absolute right, liberty rights are qualified in national and international law by reference to public health, safety, and morals as discussed in section 3.2.1. In addition, these comments noted the relational aspect of autonomy that necessitates consideration of other members of a community and should not be detrimental to others. The state has a duty to balance individual liberty against a responsibility to safeguard the well-being of all its citizens and, on this basis, the right to an assisted death could be rejected.

Some members of the Lords were aware that autonomous action in cases of requesting an assisted death is complicated by the necessity of a third party to carry out the procedure. Lord Brennan, as one example, observed the limitations of the 2003 Bill, “the Bill, while proclaiming personal autonomy is able to achieve its objective only by involving a third party-a doctor-to enable that personal autonomy to achieve the effect of its holder” (col 1610). The notion that individuals have a right to seek assistance from a third party to help determine the manner and timing of their death, extends the boundaries of personal liberty in end of life decision-making, but the absence of a third party acting in their capacity as a duty bearer could impede the possibility of an assisted death. The role of doctors was not the focus for this debate but their reluctance to act as duty bearers was commented upon,

...[t]he most recent poll of doctors, carried out on 13th May this year, established that almost three out of four doctors-some 74 per cent- would refuse to perform assisted suicide if it were legalised (col 1615).

State responsibility

Many of the Lords have legal backgrounds or long experience of sitting as representatives of one of the UK political institutions. On this basis, it is naturally expected that they would prioritise and sanction state responsibility to protect the interests of UK citizens and provide a normative framework to facilitate their well-being. Lord Plant's contribution illustrated a contemporary understanding of legal rights,

In the western tradition of legal and political thought, rights are usually thought to be assigned in terms of either protecting the choice or autonomy of the right-holder or protecting the vital interest of such a person (col 1620).

Opponents to the Bill also referred to the role of the state as in this typical example,

...the House has a duty to uphold the principle that the state has a duty to protect all of its citizens. There should be no concession from this House or indeed from any other place to those who advocate removing the right to life or the state's duty to protect human life (col 1629).

These comments highlighted state responsibility that reflects a utilitarian perspective of law-making and prioritises protecting citizens from harm. One of the key dilemmas in the debate refers to the role of the state in balancing the liberty rights of individuals as the *right-holder* against protecting the rights of the rest of society. There is great discussion in the 2003 debate over whose vital interests to protect. Maintaining prohibition on assisted death causes harm to those who are suffering unbearably and are denied assistance to die but a change in law could cause potential repercussions in wider society. The argument of Lord McColl against the Bill is indicative of the general concerns,

It is the job of government to protect the weak, the vulnerable, the elderly and the dying...no matter how carefully the bill was worded, it would prove impossible to prevent intolerable pressure, either real or believed to be real, being put on elderly people to embrace euthanasia to reduce a family, financial or nursing problem (col 1679).

This perspective was echoed by supporting sentiments from other members concerned with "family pressures of one kind or another to be exerted on the vulnerable" (col 1658) and the idea that "[m]any disabled people throughout the country feel threatened by the Bill" (col 1634). The role of government is to protect citizens, especially "the vulnerable, the elderly and the dying", but this could apply equally to both sides of the argument when the best interests of a dying patient are considered.

A UK approach to law-making promotes the common good of society revolving around majority preferences to arrive at legally binding decisions at the expense of individual liberty.

One of the main concerns expressed in opposition to the legalisation of assisted death that features in all debates and is articulated above, centres on the potential for abuse. Opponents to assisted death argue that mentally incompetent individuals or vulnerable/ frail elderly adults would be disadvantaged and subjected to assisted death without consent. This *slippery slope* would result in non-voluntary euthanasia extended to other members of society other than those proposed in the initial Bill. Members' opposition to the Bill that speculates on the views of disabled, vulnerable and elderly people suggest concern for infringement upon their liberty and decision-making ability. However, against this concern, safeguarding criteria proposed in the 2003, and indeed all Bills, cite the requirement of mental competence evaluated by two independent assessors and it would be derogatory to suggest that particular groups of individuals, namely the elderly and physically disabled, may be less mentally competent.

Right to life

Approximately half of the contributions in the 2003 debate are underpinned or associated with rights discourses, primarily through the notion of individual liberty but also including human dignity. This gives some indication that a utilitarian approach to law-making is being impacted by emphasis on, and use of, rights discourses. However, this has gone largely unremarked. Explicit reference to rights as in a *right to* something occurred seldom and there was minimal expression of assisted death specifically articulated as a *right to die* suggesting that this had not yet become a commonplace term used in the Lords, or a term chosen by members to define the debate. Where rights were discussed explicitly, they focused on a right to choose or on the scope and nature of human rights principles, primarily the nature of the right to life. The right to life *is* central to the debate on assisted dying. It defines state responsibility and, as a positive liberty right, denotes an obligation towards *all* citizens on behalf of the state. In a liberal, democratic society the right to life is presumed to extend to the right not to be killed unlawfully and to include steps to safeguard the lives of citizens including the vulnerable who may potentially be affected by a change in law. The following comment noted the conflicting role of rights,

...rights protect basic interests, and one of these is life. The issue then arises of who is to determine these basic interests. Is it the person who has the interest or are they to be defined by others? (col 1620).

Ambiguity over who should determine "these basic interests" questions the extent of personal liberty, human agency and capacity for autonomous decision-making. The right to an assisted

death is based on rational, self-assessment of the quality and value of one's own life and the freely made request to end it.

Lord Lester (col 1596) noted the discordance between current law, policy and medical practice in his call for clarity over the scope of the right to life. He approached the notion of rights from a legal perspective and critiqued the absence of reasonable legal certainty,

Patients have the right to life. They also have the right to personal autonomy and to live and die with dignity. They and their doctors need to know what exception there is to the law of homicide, enabling a doctor, acting in accordance with the patients' wishes and the doctor's judgement as to the appropriate medical treatment, to administer that treatment even though it is virtually certain that it will hasten the patients' death. Unless the criminal law and good medical practice are clear, conscientious doctors, seeking to act in the best interests of their patients, are left in a state of uncertainty, as are their patients (col 1596).

The right to life was identified here as separate from the right to personal autonomy and the right to die with dignity. The reason for these distinctions may be purely emphatic effect, but distinguishing between these concepts, each expressed as rights, presents a contrast to the legal appeals of *Pretty* and *Nicklinson* considered in the previous chapter. In common, rights discourses emphasising autonomy and dignity, are applied for the purpose of extending the scope of an existing right to life. But in this case, the intent is to gain clarity over how, with respect for autonomy and dignity, the doctor may avoid breaching the right to life compared to the case of *Pretty* that used a notion of autonomy to propose that individuals could decide to waive the right to life.

Human dignity

Rights discourses were used in the 2003 Bill as a basis to critique the current law. It was suggested that maintaining prohibition on assisted suicide

...results in grievous, prolonged and unnecessary suffering to a significant number of patients who are denied the right to remain in control of their lives until their death, and the right as they see it to die with dignity (col 1586).

The experience of a dignified death was first suggested and articulated in the 2003 debate as a *right to die with dignity*. This is a significant finding. It has implications for the terms of the debate both within legal, political, social and medical spheres where the concept of dying with dignity is prioritised as desirable. The following contributions expressed the universal and aspirational nature of dignity

Few people would argue against the view that they want to be able to die in a humane and dignified manner and above all free from pain (col 1636).

Dignity in death is something to which everyone is entitled, but there is precious little dignity in having to continue to suffer the pain, mental agony and the indignity of the loss of control of one's bodily function, sometimes for a period of months or even years (col 1649).

And the example from Lord Laing when he spoke of dying with dignity,

Which of us in the Chamber, if blind, deaf, incontinent and enfeebled in mind, would not prefer to be given the choice to say enough is enough and a doctor or nurse to do the necessary for a quick and painless death (col 1638).

Despite an assumed common desire for a dignified death, the concept of dignity was only articulated *explicitly* on a few occasions. In these contributions, dignity was mentioned in support of an assisted death though not explicitly expressed as a right. Instead, dignity, or the potential loss of dignity, was directly linked with respect for personal choice and the symptoms of serious illness that can cause great personal suffering.

An important argument, and yet one that was made on only a single occasion in the 2003 debate by Baroness Greengross (and one that she elaborated upon in 2014), referred to the right not to be discriminated against. Her argument in relation to a dignified death suggested that while able-bodied individuals had the capacity to take their own lives, the quest for dignity in dying may be limited by a physical state of deterioration or inability to end one's own life when that life becomes unbearable. The right not to be discriminated against on the grounds of disability is protected through Article 14 of the ECHR 1950 and this critique of the current law mirrored that of Tony Nicklinson (and one that was alluded to by Diane Pretty) whose contribution to the 2011 Commission on Assisted Dying was referred to in this 2003 debate. Nicklinson was quoted to say

If...I want to end my life because I am terminally ill and I want to end it with dignity in the way I feel most appropriate, then if I am able to walk, move and reach those drugs, I can do it. If I am so disabled by my illness and I cannot reach those drugs then I cannot end my life. That is discrimination against disabled people that none of us should tolerate (col 1651).

Critical summary

Analysis of the data demonstrated similarities and differences between the 1936 and 2003 debates. In common, members respected the inalienable and universal value of human life that was emphasized by a significant number of contributions both from secular and religious perspectives. A religious perspective on the sanctity of life was based upon traditional understandings of Judaeo-Christian morality. This was described in the following comment

...the deliberate taking of human life has been forbidden for centuries and is enshrined for Christians in the sixth commandment "Thou shalt not kill"...it forms an essential part of our legal system and of our way of life. To remove it would risk damaging the entire fabric of society (House of Lords, 2003 col 1665).

However, a religious position on end of life was not always identified as incompatible with assisted death. Members who supported proposals in the Bill and identified with having religious beliefs, both in 1936 and 2003, articulated their principles for supporting a change in law as grounded in the value of compassion. For example, Baroness Richardson, as a Christian questioned "[how] can we in the name of our Christian conviction deny the final mercy of shortening the process of dying of a life that has become utterly wearisome and distasteful?" (House of Lords, 2003, col 1628).

In contrast to 1936, analysis of the 2003 debate revealed that arguments have evolved to invoke human rights discourses at the end of life, generally moving away from compassion towards individual liberty to argue for self-determination over the manner and timing of death. Reasons for this are multi-factorial, some of which were expressed through this contribution

Partly because of the changes and improvements in medical practice that have occurred; partly because of the longer experience that we now have of assisted dying in other countries; and partly-and I think most importantly- because in our own society we have strengthened and statutorily codified our understanding of individual human rights (House of Lords, 2003 col 1603).

Numerous international human rights mechanisms currently offer protection for rights and these principles are enshrined on a national level through the HRA 1998, which has brought a concept of rights into the political arena and made this an accessible discourse with which to deliberate the issue of assisted death that was not available in 1936. Alongside social and economic changes, the political landscape has shifted in regard to human rights. The Universal Declaration of Human Rights (UDHR 1948) was drafted in the wake of WWII to represent a new era and revival of human rights. This drafting process was justified by the experience of the Holocaust rather than philosophical underpinning and epistemological preference in the merits of God, nature or reason for defending its values (Morsink, 1993). Other international human rights mechanisms have since developed that encompass not only civil and political rights but also economic, social and cultural rights to afford protection for the rights and freedoms of vulnerable individuals or groups of individuals. The proliferation of international and national human rights instruments has provided a new opportunity and language structure with which to debate complex, contemporary issues.

Following the 2003 debate, there was an intense period that focused on end of life provision and the role of palliative care services. Bills were proposed, once again, by Lord Joffe and assisted death was debated in the House of Lords in 2004 and 2006. In 2006, the debate largely discussed palliative care provision and for this reason is not analysed in-depth here. From 2006, the issue of assisted death became increasingly visible and discussed in the public sphere. The newly renamed organisation Dignity in Dying (formerly the Voluntary Euthanasia Society) increased their campaign efforts and, through close collaboration with Lord Falconer, the Assisted Dying Bill 2014 was proposed.

6.3 Assisted Dying Bill 2014

The Assisted Dying Bill 2014 was brought forward by Lord Falconer with the proposal to “[e]nable competent adults who are terminally ill to be provided at their request with specified assistance to end their own life” (Assisted Dying Bill 2014). Prior to this Bill, in 2010, the Commission on Assisted Dying (hereinafter The Commission) was established to consider whether the current law on assisted suicide in England and Wales was fit for purpose. Unlike the House of Lords Select Committees, this was not a Parliamentary instigated commission.⁵⁷ It was chaired by Lord Falconer after being set up by the British think tank Demos, who responded to a privately funded tender from the late Terry Pratchett and Bernard Lewis; a relationship brokered by Dignity in Dying (Commission on Assisted Dying, 2012). The scope of the Commission included:

...a public call for evidence which received over 1,200 responses from practitioners, professional bodies and members of the public; six public evidence meetings to gather oral evidence from experts and individuals with relevant experience; international research visits to four jurisdictions in which some form of assisted dying is legally permitted; original research on the relationship between suicide and serious physical illness and into attitudes on assisted dying among people from ‘vulnerable groups’; and commissioned research on the effectiveness of legal safeguards, and the quality of palliative care, in jurisdictions that permit some form of assisted dying (Commission on Assisted Dying, 2012).

⁵⁷The credibility of the Commission was also referred to by Lord Justice Toulson in the *Nicklinson* judgement,

...it is important to stress that it was not an officially appointed commission. Its report contains an interesting analysis of arguments and views, but it would not be right for the court to treat it as having some form of official or quasi-official status (*Nicklinson v Ministry of Justice* [2012] EWHC 2381).

The Commission published their report in January 2012 unanimously proclaiming the current legal status on assisted suicide in England and Wales to be “inadequate and incoherent” and suggested an alternative provision that was used to inform the content of the Assisted Dying Bill 2014 (Commission on Assisted Dying, 2012). Lord Falconer as Chair of the Commission emphasised a claim to neutrality through not inviting members identified as having a principled stance on the issue of assisted dying (Commission on Assisted Dying, 2012), but there were accusations of bias and lack of transparency by those opposing assisted death including the Care Not Killing alliance and the Church of England General Synod. In the introduction to the Assisted Dying Bill 2014, the words of Lord Falconer mirrored those used by Dignity in Dying in their campaign to legalise assisted death claiming “those who are terminally ill should have choice over where they die” and legal change “would lead not to more deaths, but to less suffering”. The nature of the relationship between Dignity in Dying as a campaigning organisation and their ability to influence political collaborators and to define the issue on the political agenda is an interesting research focus and one that is discussed in the following chapter.

6.3.1 The 2014 debate

In comparison to the 2003 debate that occasionally articulated rights discourses explicitly as the right to choose, or through discussion of the scope of an already established right to life, the depth of arguments in the 2014 debate have been strengthened and advanced by what appear to be a richer and more widely recognised, used and developed notion of rights. Influenced by high profile legal cases, extensive media involvement and vociferous activities of campaigning organisations, the debate was gaining momentum and public sentiment appears to have shifted more in favour of increased choice to determine end of life. This change was reflected in the 2014 debate. Arguments were primarily grounded in individual liberty to underpin and enhance the value of personal autonomy in regard to end of life decision-making. In addition, deliberation of specific rights including the right to life, the right not to be tortured or subject to inhuman or degrading treatment, and the right not to be discriminated against were also raised in the 2014 debate. Analysis of the contributions revealed a division between strong personal convictions highlighting rights as individual freedoms, weighed against concern for the safeguarding provisions of the Bill with regard to the impact of legal change upon other members of the community.

One new theme emerged to dominate the content of this debate. There were many moving references to personal experiences of severe and chronic illness or loved one's dying by the Lords themselves or through letters received from the public. Personal opinion was coded as a category for analysis independent of rights discourses. However, a large number of these personal appeals focused on motivating members to consider the dilemma in terms of rights.⁵⁸ These contributions through their emphasis on aspects of rights including human dignity and the experience of unbearable suffering, did serve to strengthen the arguments made by some members of the Lords for respecting individual liberty in the end of life decision-making process.

Rights

In contrast to previous debates, analysis of the 2014 debate revealed that member contributions seemed accustomed to the concept of human rights and naturally articulated their arguments in terms of rights. It was clear that rights discourses had become familiar language with which to debate the end of life. A number of contributions elevated the ethical status of assisted death by positioning the right to die alongside other rights and fundamental freedoms recognised in a liberal, democratic society. Baroness Blackstone, for example, by way of supporting her arguments for a right to die, aligned it with other legally recognised rights reflecting the current social context. She claimed

We live in a society that promotes individual autonomy and values allowing its members to choose how they spend their lives. We value freedom of speech, of association and of movement. We value tolerance and allowing people to make their own choices even if we wish to make different choices. The same freedom of choice that applies to how we live should also apply to how we die. If we respect human rights, we should not deny those who know they are dying the right to bring their lives to a more rapid end to alleviate their misery (col 804).

In this comment, rights are understood to involve human freedoms and this is extended to the prospect of achieving a more dignified death. Rights were used interchangeably in the 2014

⁵⁸ As part of the 2014 campaign initiative, Dignity in Dying, supporters were encouraged to lobby peers for a change in the law and such a high level of public sentiment may have prompted the Lords to deliberate the issue more seriously. During the debate, many Lords read out extracts from letters they received from the public reflecting upon their tragic and distressing experiences. Lord Philips commented

...all of us have had extraordinarily moving letters- not Cyclostyle letters with just a name at the beginning and a name at the end, but very particular, individual and moving letters. I am sure they have moved all of us and given us more wisdom and determination to scrutinise this bill in subsequent readings to make sure that if it goes through, it goes through in the best possible form (House of Lords, 2014 col 879).

debate. There was evidence of fluidity in conceptions of rights that, at times, included grounding rights both in a foundational and anti-foundational understanding. In the example below, rights were articulated in connection with their legal status, a *right to make up ones' own mind* and a *right to die in peace* were formulated in the context of legally recognised rights

The right to die in peace is surely a personal choice that should be upheld and recognised in law. It is wrong that a person should be forced to endure great suffering because of the genuinely held strong views of others. We live in a democracy where citizens have the right in personal matters to make up their own minds and to act accordingly. Society should respect and protect the right to choose how you wish to die in the same way we respect other important personal freedoms (col 882).

The following excerpts demonstrate that even when presenting arguments against the legalisation of assisted death, rights discourses were adopted. In effect, the language of rights is now informing both sides of the debate. The egoistic nature of rights was criticised and the extent of individual liberty rights questioned in regard to whether protection of individual rights, or the rights of a small group of terminally ill individuals, should be at the cost of the rights of other members in society. The contributions below are indicative of this sentiment

...law is about more than a small group of individuals' rights against the state. Herein lies the main weakness of our human rights law; it fails to take into account the rights of the rest of society (col 898).

Much has been said about autonomy in this debate- about our right to take decisions about our lives. But all too often it ignores the reality that what we do or omit to do affects others... The reality is that all of us are part of a wider society. What we say or do affects others. Importantly our attitudes and decisions are influenced by those around us (col 869).

Members who did not support a change in law also argued in terms of rights to refute the right to an assisted death, rather than selecting alternative discourses of compassion or need. Lord Shipley (col 858) considered the principles of an individual right to request assisted death. This would be his own choice, but as a law-maker he felt duty bound to consider the well-being of others,

...in principle I believe individuals have a human right to exercise their own choice to end their own suffering. It is a right that I would like for myself to be taken with my family. But that right for me does not mean that it must transcend the human rights of others to safety and security under the law. No person should feel threatened by any change in law (col 858).

Opposition to a right to die, throughout all debates, was generally informed by the potential consequences of legal change and the difficulty in democratic society of balancing the rights of individuals without impinging on the rights of others. In 2014 this dilemma was the main focus of both sides of the arguments in the debate. While earlier debates articulated this as regard for the safety or well-being of others, in 2014 this was typically articulated through rights discourses. This is an important finding that clearly demonstrated the extent to which rights have come to dominate the issue of assisted death. Analysis of the data suggests, on this issue at least, a potential move from law determined by utilitarian tradition to one that is determined by rights.

Arguments in the 2014 debate recognised the complexity of the assisted dying dilemma in regard to the interpretation and scope of other rights. In general, the contributions illustrated an awareness of rights recognised in legal mechanisms. In contrast to the earlier debates, there appeared to be a willingness to deliberate the appropriation of these rights and apply them in an end of life context. As one example, the ambiguous nature of the right to life, as posited by the appeal of *Pretty* in the previous chapter was addressed by Lord Judd

...if you believe in the right to life and that it must be protected at all costs, you cannot dodge the secondary question of what life is. If a person has reached the stage at which they say “What I am going through and experiencing cannot be described as life as I understand it” how can those of us who believe in life, if it is to have any sense, meaning or fulfilment, possibly reject that request? (col 884).

Baroness Tonge, drew upon another right claimed by *Pretty* in her application to suggest extending the boundary of an existing right to protect the dignity of severely disabled and chronically ill individuals, who “are in the words of Article 3 of the European Convention on Human Rights, being subjected to torture or to inhuman or degrading treatment. Should we allow this?” (col 822).

In this 2014 debate, the concept of dignity was referred to *implicitly* as a component of human rights principles and on occasion, in relation to impingement upon other rights. Lord Falconer was one of the few members who specifically articulated the importance of dignity and argued that individuals who request assistance to die are often not motivated by pain “but the loss of independence and dignity” (col 775). Denial of a dignified death on the grounds of physical disability preventing an individual to commit suicide is directly linked to rights through violation of the right not to be discriminated against. Baroness Greengross reiterated this point made in the earlier 2003 debate as she aligned her argument with the current legal

provision under the Suicide Act 1961, which permits people to commit suicide, but, in the case of physical incapacity, this right is restricted. She claimed

...the Bill is not a case of giving someone a new right. It is just the opposite. Without it at its most basic we are going to deny certain people who are terminally ill and have become disabled the right that every other adult has in this country: the right to terminate their life (col 786).

There were, on a very small number of occasions, Members who completely rejected a concept of rights as applied to the debate. The comment by Lord Tebbit is particularly clear

We have to be careful of the words we use. I noticed that the noble Baroness Lady Greengross referred several times to the “right” that we all have to take our own lives. We do not have that right; we have only the capacity to do it (col 788).

Lord Tebbit’s critique was dismissive of the so-called right to end one’s own life and replaced this with the notion of capacity, offering an alternative foundation for understanding end of life issues not articulated as rights. His contribution did not expand upon this position but personal views may be shaped by individual backgrounds and values that can be indicative of an orientation towards rights in general or the right to die in particular.⁵⁹ Perhaps unsurprisingly, considering the advanced age of many of the Lords, the adoption and use of rights discourses which is increasingly indicative of a contemporary approach to complex dilemmas, was, on occasion, prey to disregard. Lord Maginnis was also one of a minority who explicitly criticised a human rights approach through the fashion “systematically to discard every accepted rule for living in a civilized society and to replace them with a collective of legislation allegedly designed to promote human rights” (col 1644).

Other comments did not completely reject concepts grounded in rights discourses but remained sceptical of a notion of rights that encompassed unrestricted liberty. This was expressed from both secular and religious perspectives. Traditionally, a religious perspective prioritised the will of a sovereign God over individual choice to determine matters of life and death, but there were also secular critics of an idealised notion of choice,

I know that choice is the great aim of our age- choice in all things, as though we were all shopping. But who gets the choices? How many people in our communities have real choice? The issue of choice is a snare and a lure...Our society is becoming a harder

⁵⁹ In the run up to the 2014 debate, Dignity in Dying compiled a list of peers for their members to lobby based on their specified or supposed (through previous voting history) positions on assisted dying. The results are located in table format in Appendix 3 and demonstrate that 112 Conservative peers compared with 61 Labour and 24 Liberal Democrats were opposed to the Bill. Political allegiance that defines positions on assisted death and perspectives on understanding rights at the end of life is an unexplored and potentially interesting focus for further study.

place-harder on the elderly, the young, offenders, the unemployed and the poor. Society is full of people who have very few choices (col 874).

This observation was raised in section 2.2.3 questioning the true extent of choice in end of life care and in the previous chapter where law and policy curtails freedom of choice in permitting third party assistance to die. Under current UK law and policy, and common to proposals in this Bill and the preceding Bills “people who have very few choices” include those who are not deemed mentally competent to request or refuse medical treatment, those under 18 years old and those who cannot communicate their wishes.

Analysis of the 2014 debate revealed less opposition on the basis of religious arguments than in previous debates, perhaps reflecting the generalised trend of declining religiosity in England and Wales or the expanding remit of individual liberty regarding personal freedoms in contemporary society. Referring to the personal letters received prior to the debate, reasons suggested for an apparent increase in support for assisted death were postulated

I felt that the arguments in the letters represented a big shift in thinking away from deference towards professionals such as doctors and politicians, and maybe even the church, and towards a stronger belief that individuals with their families should be able to exercise greater control over their own lives. There is an increasing reluctance to let others decide our fate (col 868).

This “deference towards professionals” has been challenged by an increase in healthcare consumerism and alternatives to the medical model, supported by increasingly individual negotiation of lifestyle choices and an awareness of rights in relation to healthcare that is grounded in respect for personal liberty and dignity. A “stronger belief” in individual control over our own lives outside of the legal and medical domain may be perpetuated by what Turner coined the “precariousness of social institutions” when he argued that technology and social modernity have changed the circumstances of human ontology and modern life is now subject to a range of diverse threats and challenges (Turner, 1993:502). At the end of life especially, human beings are vulnerable. The dying body is subject to protection or exploitation by institutionalised or legal rights and practice. The desire to self-determine the dying process grounded in the right to individual liberty may be a reflection of the evolving relationship between contemporary society and social institutions.

The 2014 debate was notable in that an increased number of faith leaders, and others who expressed their faith willingly, vocalised their support for assisted dying. There are 26 Bishops in the House of Lords that form the Lords Spiritual. These Bishops provide an important

independent voice and spiritual insight to the work of the Upper House and postulate that they seek to be a voice for all people of faith, not just Christians (Church of England, 2014). Assisted dying is a contentious issue that challenges traditional religious doctrine and the 2014 debate observed this growing division within the Church of England,

The church seems divided on this issue and rightly talks of the sanctity of life. There could be no greater subscriber to the sanctity of life than me, but surely part of that sanctity is constituted by-how can I put this?-a sacred stillness, a dignity, a precious humanity that is undone by rendering a dying human being into a screaming animal, a shadow of their former and real self, utterly deprived of the inalienable right of personal autonomy (col 872).

This position was shared by other members from both a religious and secular basis, not only respecting the sanctity of life, but also supporting the sanctity of life through the realisation of an assisted death. In common, they emphasised respect for the inherent and universal dignity and liberty of the dying individual to determine when their life has become unbearable. This was an interesting development in the debate. Assisted death was not articulated as mercy killing. Instead a religious conception of the sanctity of life was challenged by an understanding of rights that grounded moral claims through a secular desire to relieve suffering and to respect individual autonomy.

Perhaps the most spectacular revelation was made by the former Archbishop of Canterbury, Lord Carey, who was interviewed for the *Daily Mail*⁶⁰ a few days prior to this debate initiating the front page headline "Carey: I've changed my mind on right to die" (*Daily Mail*, 11th July, 2014:1). Lord Carey defended the opinion expressed in this article during the debate asking

...how can I really repent of a decision that I believe more closely models and reflects God's mercy and love...When suffering is so great that some patients, already knowing that they are at the end of life, make repeated pleas to die, it seems a denial of that loving compassion which is the hallmark of Christianity to refuse to allow them to fulfil their own clearly stated request...If we truly love our neighbours as ourselves, how can we deny them the death that we would wish for ourselves in such a condition (col 847).

The argument is not explicitly grounded in rights but refers to compassion (one of the few occasions where compassion surfaces in this debate). Compassion is, however, linked with the denial of individual liberty and used to support an assisted death through respect for the wishes of the dying to end a life of suffering. In relation to his own background, Lord Carey associated the notion of compassion with a Christian perspective; a different basis than rights,

⁶⁰In the few weeks prior to the 2014 debate, the *Daily Mail* newspaper ran a series of articles quoting support from high profile individuals in favour of a right to die, including some who had quite dramatically reversed their opinion on the issue.

but at the same time acknowledged individuals as having the capability or potential to want reasonably to determine the timing of their death under intolerable conditions. As a former Archbishop, the contribution of Lord Carey is especially significant and influential in that he disputed the religious arguments against assisted death and claimed that prohibiting assistance to die in cases of unbearable suffering was not indicative of a merciful and loving God.⁶¹

Personal experience

In 2014, a new topic was introduced that came to dominate the debate; the Lords own experiences of illness and disability or the deaths of loved ones. This was particularly interesting because the sharing of such personal circumstances had not previously featured in the debates and was now openly being discussed in a major political institution. Some read out postbag letters, others referred to their own experiences. It demonstrated the extent to which this topic has permeated the public and political consciousness. Although these contributions were not always argued or contemplated using rights discourses *explicitly*, the nature and degree of suffering at the end of life was often described in detail. It was suggested that a distressing or bad death was defined by an unbearable experience of suffering and lack of dignity. This implied an understanding of suffering as a human rights issue through the link with dignity and indignity. Examples included:

...in the end she was in a hospital bed begging for help. She was in agony. I too, begged for help; I ran around the hospital trying to find a medic that would do something. But they argued that she was getting as much morphine as they dared to give her, that any more would be illegal and that they could not help (col823).

My mother and mother-in-law both had long drawn out deaths, which in the case of my mother-in-law was accompanied by great suffering. In the end both took the only way out that they could by starving themselves to death (col 836).

Some members did derive their position in the debate from their own experiences defining this through rights,

⁶¹ His position caused outrage among the Church of England, but the views of Lord Carey were not easily dismissed. Elaborating upon remarks made in House of Lords during the 2014 Assisted Dying Bill, he later reaffirmed his stance ahead of the 2015 House of Commons Bill arguing

There is nothing noble about excruciating pain and I think we need as a nation to give people the right to decide their own fate...And in my view it is a profoundly Christian and moral thing to devise a law that enables people, if they so choose, to end their lives with dignity. (*The Telegraph* 12th August, 2015) [online].

I can see no reason at all for denying individuals the right to manage their own imminent, irreversible and prospectively painful, wretched or deeply distressing death- in their own interests and in the interests of loved ones they will shortly leave behind (col 803).

Analysis of personal stories described in the 2014 debate suggested that the experience of suffering is increasingly being drawn into the end of life debate and articulated as part of a rights discourse through the association with concepts of choice and dignity, or, in some cases, an undignified death. Human suffering, as expressed through the personal letters, highlights the vulnerability of the body. In the dying process, all individuals face an unknown amount, intensity, and manifestation of suffering and this experience renders them frail. The phenomenological experience of suffering and the aspiration of a dignified death appeared to justify the concept of rights in an end of life context for some members of the Lords.

Critical summary

The 2014 debate was on a grand scale. One hundred and thirty three members of the Lords spoke and even those who had not previously engaged with the debate, or had no firm position for or against the Bill, chose to participate. Such a high level of involvement confirmed that the issue of assisted death has become one of profound social and political importance. The prevalence of human rights discourses used to express arguments both in support and opposition to a legalised right to request assistance to die was greatly increased in comparison to the 1936 and 2003 debates and illustrated that this is now the terrain upon which the issue is debated. This finding is both interesting and significant in so far as human rights discourses that ground an understanding of individual liberty appear to have replaced a utilitarian approach to law-making as the dominant tradition in the UK. The findings of the data that characterise the discourses used and arguments that advance or constrain requests for assisted death in the historical 1936 debate, the 2003 debate and contemporary 2014 debate are summarised in the table below.

Figure 6.2 Comparing discourses and arguments of the 1936, 2003 and 2014 House of Lords debates

Legalisation of assisted death	Historical 1936 debate	2003 debate	Contemporary 2014 debate
<i>Supported by</i>	Compassionate discourses, “mercy killing”	Individual rights, the “right to choose”	Comprehensive articulation and understanding of liberty rights
<i>Opposed by</i>	Faith-based discourses that express religious position on sanctity of life.	Concern for wider society, protection of the vulnerable from abuse and fear of a slippery slope	Concern for unrestricted liberty and protection of community rights over individual rights and
<i>Aims to achieve</i>	“quick and painless death”	Relief of suffering and respect for autonomy	Respect for autonomy and “right to a dignified death”
<i>Challenged by</i>	Duties of a doctor to “cure and not kill”	Medical model of care especially palliative care	Debate over extent of right to self-determine best interests
<i>Would protect</i>	Rational free will and against intolerable suffering	Individual autonomy and against an undignified death or protracted suffering	Right to die on same basis as other fundamental freedoms; privacy, association, speech, anti-discrimination

Conclusion

The issue of assisted death has been examined through a historical and political perspective on the House of Lords Bills and debates. This chapter has highlighted the arguments and

contributions of the Lords in relation to proposed legal change and assessed the language with which their positions in the debates were articulated. The content of all Bills has remained similar over time, proposing legal change to enable mentally competent, dying individuals to request assistance to die. Since 2006, emphasis has been on self-administration of lethal medicine to better reflect individual, informed choice. There was, however, a notable contrast between the initial and later debates demonstrating how language used in the contributions has developed to reflect the context of dying at a particular period in history. The 1936 debate was not defined by rights discourses. There was minimal articulation of rights, and rights were only referred to explicitly in two comments. Instead, the main focus was on a compassionate response to alleviate the suffering of those nearing death and this notion of compassion was grounded in Christian values. Arguments against assisted death cited respect for the sanctity of human life that was in the hands of a sovereign God. The positions in the 1936 debate were defined and determined through closer adherence to religious frames of reference, representative of this time.

In contrast, the contemporary arguments in relation to legalisation of assisted death more commonly adopted rights discourses to underpin their values and beliefs. In particular, arguments in the 2014 debate drew upon an understanding of rights involving individual liberty and human dignity to justify their support for or against legal change. The contributions primarily centred on the interpretation and boundaries of individual liberty rights encompassing personal autonomy in end of life decision-making. This suggests that human rights discourses have proliferated and become more commonplace in this particular political forum. Complex issues, that now include the end of life, were discussed in terms of rights and in this way rights discourses were considered central to the contemporary assisted dying debates. Analysis of the data in this chapter demonstrates how rights discourses have, to a large extent, replaced compassionate and faith-based discourses over time in the context of death and dying.

In the 2003 and 2014 debates, many contributions argued from a human rights perspective. However, understandings of rights were found to be inconsistent and variable depending on individual interpretations. A number of members in the contemporary debates appeared to understand rights at the end of life only in a legal context, while others articulated components of human rights discourses with specific considerations in the debate such as the right to maintain human dignity in the face of intolerable suffering and yet others constructed

their own interpretation of rights, for example “a right to choose” or “right to die in peace”. Some members who disputed or opposed a right to die even employed rights discourses to express their opinions or used an understanding of particular rights to enhance their positions. Concepts of individual liberty grounded in rights were used to support self-determination at the end of life. Equally, the protection of individual liberty was used to argue against the legalisation of assisted death on the basis of undermining or threatening the rights of others in society who may be at risk from abuse. Members of the Lords could also be sympathetic to articulating claims as rights and employ both foundational and anti-foundational aspects of human rights to enhance their arguments, without necessarily supporting all human rights principles or claims to rights. Rights discourses, especially in the most recent 2014 debate were widely used, albeit in complex and inter-related, sometimes unrelated ways. It is now apparent that human rights discourses have become central and are essential to defining the terms of the debate. Rights discourses were used extensively in the House of Lords in regard to negotiating the issue of assisted death, but rights were understood and interpreted in different ways.

The House of Lords has the ability to propose and deliberate legislation on end of life. Members are important social actors who can contribute to shaping public opinion and conduct, and determine legitimate standards of behaviour. However, the Lords represent a political institution. As individuals they are not entirely independent. Their lives are not conducted in a social vacuum and they are not insusceptible to outside influence and prevailing discourses. On this basis, it was relevant to examine other social actors who may impact the ways in which assisted death is thought about and deliberated in the House of Lords. Members of the Lords, namely Lords Ponsonby, Joffe and Falconer proposing the 1936, 2003 and 2014 Bills respectively have each collaborated with, and been supported by, Dignity in Dying (formerly the VES), an organisation that promotes and actively campaigns for the legalisation of assisted death. Dignity in Dying have a role in informing public perceptions on end of life. They have strategically generated a high level of public engagement including the lobbying of peers through personal letters and this had a demonstrable and significant effect on members’ contributions to the 2014 debate. The activities and intentions of Dignity in Dying could include shaping the opinion of both the public and the lawmakers through their campaign strategies. For this reason they were selected for closer analysis. The findings of the case study are discussed in the following chapter.

CHAPTER 7

Case study on Dignity in Dying

Dignity in Dying (hereinafter DiD) are a well-established, national organisation that campaign to change the law and realise the right to an assisted death. They hold, as an objective, “to legalise assisted dying within upfront safeguards for terminally ill, mentally competent adults” (DiD, 2016). DiD were selected for a case study on the basis of their historic foundation, significant reach, and ability to stimulate debate on a right to die in the public and political arena. Not all members of UK society will be familiar with the organisation as such, but most will be aware of the notion of a right to die, legal debates on the issue, and media reported cases where individuals have requested an assisted death. Dignity in Dying offices are based in London. The current structure of the organisation includes nine permanent staff members and a number of volunteers who work under the direction of a Chief Executive, Sarah Wootton. DiD have substantial financial backing; there are over 25,000 members on record and this generates income that for 2014 totalled £2,163,141.⁶²

Considering the atypical focus of their campaigns and relatively small number of employees, Dignity in Dying have spectacularly impacted the landscape of death and dying through raising end of life concerns in the public sphere. Their endeavours have achieved national coverage of assisted death on mainstream television news and in newspapers and prompted, or persuaded, high profile figures to speak out in support for their aims. The organisation has throughout its’ history worked closely with political figures, most recently including Lords Joffe and Falconer, both former lawyers, with whom they drafted the 2003, 2006, and 2014 House of Lords Bills. Affiliation with peers in the House of Lords has lent political credibility and power to their objectives and DiD has identified, as a target for their campaign efforts, political institutions that can instigate legal change. DiD are a key social actor in the assisted death movement. As a historic organisation that campaigns for social change on one exceptional

⁶² This was broadly broken down as 33% from member subscriptions and general donations, 23% from legacies, and 40% from high net worth individuals (DiD Trustees Report, 2015:5).

issue, in-depth analysis reveals a unique insight into understanding rights discourses in an end of life context.

The purpose of this chapter is to present a case study analysis of Dignity in Dying as a campaigning organisation that has a specific focus based on clear guiding principles. The chapter will examine *how* and *to what extent* human rights discourses are used by DiD and *why, or for what purposes*, they incorporate the language of rights in an end of life context. Analysis of rights discourses and the use of a rights frame in relation to campaign strategies, demonstrates how rights can be applied within a new context to define the issue of assisted dying. The case study of DiD supports and builds on Miller's (2010) contribution that develops alternative ways of using rights outside of "rights-based approaches" and confirms that a "one size fits all" label cannot be applied. This chapter is divided into four sections. The first section introduces the organisation through its foundations to set the context for Dignity in Dying. Their aims and objectives are discussed in the second part of the chapter. The third section analyses the discourses used in mediated communication through an example of their newsletter and the website at the time of the 2014 House of Lords debate. The fourth part of the chapter explores the voices of Patrons and the public through their personal narratives considering how their language legitimises and embeds the values of DiD.

7.1 Foundations of the organisation

Dignity in Dying was originally established in December 1935 by Dr Charles Killick Millard under the name The Voluntary Euthanasia (Legalisation) Society (VES). Members of the first VES Executive Committee included medical consultants, academics and Christian ministers whose intention was, not to build a popular movement, but rather a "network of distinguished sympathisers able to influence policy at high levels" (Kemp, 2002). The Society at this time consisted of a Consultative Medical Council and a Literary Group, and was endorsed by a variety of authors, progressive reformers, and feminists (Kemp, 2002). Catalysts for the emergence of a euthanasia movement in the UK are difficult to specify, as are the ideological foundations of the organisation. The literature is very limited in relation to this. It is thought that social reformer Annie Besant was the first to raise the issue of euthanasia in the 1870s as a social duty to society to "die voluntarily and painlessly" when one reached the point of becoming "a burden" (Dowbiggin, 2007:51). Kemp (2002:119) suggests that pre-1936 arguments supporting voluntary euthanasia were driven by an intellectual stance on eugenics

and a desire to reduce the prevalence of feeble-minded and mentally defective individuals in society, promoting “survival of the fittest”.

In particular, Dr Charles Killick Millard was instrumental in placing the issue of assisted death, or voluntary euthanasia as it was then termed, on the political agenda, when he proposed the first Bill for the legalisation of voluntary euthanasia in his Presidential Address to the Society of Medical Officers of Health in October, 1931. His contribution demonstrates how a concept of rights underpinned the early arguments for an assisted death when he emphasised that the act “should be regarded not merely as an act of mercy, but *as a matter of elementary human right*” (Millard, 1931:12). This is a significant finding. It appears to have been the first time euthanasia was thought of as a personal “right” and the right to die had been articulated as such. Expressions of rights at this time appeared limited in comparison to a contemporary, UK context. For example, the suffrage movement had campaigned for equal rights and won women over the age of 30 the right to vote in 1918, and this was extended to all women in 1928. In 1919, the International Labour Organisation was founded with the aim of protecting workers’ rights (ILO, 2016). However, realisation of these objectives were articulated through liberal conceptions of equality and social justice rather than individual rights *per se*. Pre-Universal Declaration on Human Rights (1948), expressions of *rights* understood as *human rights* were minimal. Rights were more commonly associated with political and economic freedoms, rooted in the political revolutions of the previous centuries, rather than concerned with personal or ethical dilemmas.

Some understanding of rights has been apparent throughout the history of the organisation. Considering the backgrounds of members of the Committee and the position of Killick Millard, who had also supported the extension of other individual liberties such as birth control, the early foundations of the VES could suggest a right to assisted death grounded in classic liberal ideology. Millard died in 1952, but his indication of a human rights approach to assisted death was demonstrated throughout the 1950s. By the 1950s, and more so in the 1960s, a notion of rights that entailed individual liberty had moved into focus, especially in regard to legislation of personal issues. From 1955 onwards, the organisation became known as the Euthanasia Society. As part of its campaign activities at this time, the Euthanasia Society placed adverts on the London Underground and on mainline railway services in the south of England, with the wording “The Euthanasia Society believes that incurable sufferers should have the right to choose a Merciful Death” (Kemp, 2002). This campaign message highlighted an individual

“right to choose” in relation to incurable illness, which bears a remarkably consistent resemblance to the rhetoric and ideology of the organisation today. *Choice* over the manner and timing of one’s death was, and is, prioritised, especially in cases of terminal illness.

The most recent name change occurred in 2006 when the organisation became known as Dignity in Dying.⁶³ From this time onwards, DiD centralised the value of human dignity and clearly positioned the act of assisting death to be understood in terms of rights (to the extent that human dignity is understood as a human rights issue). The emphasis on *dignity* by DiD was strategically employed to advance their aspirations and transform the terms of the debate through linking the option of assisted death with a dignified death. Emphasising a more universal aspiration of dignity in dying could also be construed as an attempt to lessen controversy, demobilise antagonists, and increase the appeal of assisted death. This use and interpretation of dignity reflects the official approach of the organisation based on values that have remained historically consistent. Permitting an assisted death would enhance individual rational choice, potentially alleviate great suffering and facilitate a more easeful and dignified death that would respect the humanity of seriously ill and dying persons.

7.2 Aims and objectives

The overall aim of the organisation has not significantly changed in the 81 years since it was founded. It has consistently held as an objective to legalise an assisted death in cases of incurable or terminal illness. Following the House of Lords Bills proposed by Lord Joffe in 2003, 2004 and 2006, and renewed interest in the issue of assisted dying from this time onwards, the activities of Dignity in Dying have amplified. The focus of more recent campaigns has specifically utilised rights discourses. In 2014, the primary aim of the organisation was “to change the law to allow the choice of an assisted death for terminally ill, mentally competent adults, within upfront safeguards” (DiD a, 2014). The objectives of DiD are stated on the Home

⁶³ Prior to this, palliative care had routinely used the phrase “dignity in dying” at the end of life to define their holistic approach encompassing respect for the physical, emotional, and spiritual care needs of the dying. The name change was heavily criticised by opponents to assisted death, including, as one example, the contribution of The Lord Bishop of St. Albans who claimed that the name change

...seems to imply that there is only one dignified way to die-by euthanasia or assisted suicide. The organisation has taken a phrase that is used in palliative care and by the hospice movement and has turned it around to mean the exact opposite of what it originally meant (House of Lords, 2006 col 1211).

page of their website under “About us”. Their “vision” that has remained consistent over the four year period of study is articulated as follows

We believe that everyone has the right to a dignified death. This means:

- Choice over where we die, who is present and our treatment options;
- Access to expert information on our options, good quality end-of-life care, and support for loved ones and carers;
- Control over how we die, our symptoms and pain relief, and planning our own death.

The first two objectives of “choice over” and “access to” end of life care strategically mirrors provision in the NHS Constitution 2013 and the End of Life Care Strategy 2008 discussed in Chapter 5. The findings revealed choice over and access to good quality end of life care to be already defined and protected by UK policy. Kingham and Coe (2005: 148) argue that whilst campaign aims must be bold to generate momentum, internal objectives must be realistic in order to achieve progress. This is exemplified by the first two objectives of DiD that are attainable and have wide appeal, without being too specific. The availability of end of life resources may vary, and, due to the fluctuating nature of serious illness, the place of death may be difficult to determine. However, as illustrated in section 5.4.2, there is documented provision in government policy for some end of life decisions that afford a degree of autonomy in dying.

End of life issues are complex. The objectives above demonstrate how a problem can be deconstructed and specific solutions or stages of solutions are identified that already are, or could be, achievable within the current political context (Kingham and Coe, 2005:25). Citing “control” over how we die as the third objective of the organisation is a powerful discursive strategy suggesting a natural progression of choice. It is implied that “access” should extend to and include, control. In order to achieve the third objective, “control over how we die”, DiD campaign tactics focus on emphasizing the limitations of current law. This aspect has been driven by media coverage and public focus on high profile cases where individuals have been denied a dignified death through conflict with current statutory law and policy provision. As the values of choice and control, underpinned by the notion of healthcare consumerism and patient participation become more prominent in contemporary society, not being able to control the manner and timing of one’s own death is projected as increasingly problematic.

7.3 Campaign for Dignity in Dying 2014

Kingdon (2003) suggests opportunities will arise where campaign efforts are likely to attain maximum impact and these opportunities may be triggered by current or historic events which are experienced and/or reported as problematic. In relation to assisted death, a number of factors have created optimal conditions for achieving change in the period 2011-14. These include: the high profile legal appeals publicised by the national media in 2011-2012 of Tony Nicklinson; the publication of the privately funded *Commission on Assisted Dying Report 2011* that criticised current end of life provision as “inadequate and incoherent”; the emphasis on “choice” and “dignity” in the NHS Constitution 2013; controversy over, and later phasing out of, the Liverpool Care Pathway;⁶⁴ and finally, the lead up to the Assisted Dying Bill 2014. These separate events together with a socio-cultural shift supporting individual rights and perpetuated by increasing healthcare consumerism, collectively paved the way for, and directed, renewed effort into the 2014 campaign for DiD. Mediated communication utilised by DiD in the period prior to the Assisted Dying Bill 2014 included information on their website, distribution of leaflets, published newsletters, poster advertisements, on-line petitions and picketed demonstrations outside Westminster. This section explores the typical discourses used in one example of their newsletter and on their website pages during the 2014 campaign.

7.3.1 Newsletters

Newsletters titled “Campaign” were, and continue to be, published three times per year. These are electronically distributed to existing members and to any interested parties who request this through the website or telephone contact. Hard copies are also available at the Dignity in Dying office and can be accessed at their events and the Annual General Meeting. Rights discourses were evident in these publications and are utilised specifically to target an intended audience who support, or may be persuaded to support, the aims of the organisation. One example of their newsletter selected here (issue 3 of 3, 2014) was distributed in the wake of passing the Assisted Dying Bill 2014 at Second Reading stage in the House of Lords. The content that is typical of the other newsletters includes thanking supporters, campaign updates, explanation of legal issues at end of life, personal stories, information on past and

⁶⁴ Following concerns by bereaved relatives, the Liverpool Care Pathway for the Dying Patient (LCP) was phased out during 2013. Instead, the Leadership Alliance for the Care of Dying People (LACDP), a coalition of 21 national organisations, was established with the remit to lead and provide a focus for improving the care of people who are dying and their families. The LACDP produced a document that is currently in use detailing 5 new “Priorities of Care”, setting out standards of care for the dying in 2014-2016 (NHS England, 2014).

upcoming meetings, and foregrounding high profile voices who support their objectives (see Appendix Three).

Figure 7.1 2014 Dignity in Dying campaign newsletter, issue 3 of 3



Examination of the information and articles in the newsletter revealed rights discourses to be used extensively. Rights were articulated explicitly with reference to rights that feature in legal statute and a *rights frame* was used to emphasise ideals of choice and dignity. Framing is a key concept used in campaign strategies and is defined by Gramson (1989) as “a central organising idea for making sense of relevant events and suggesting what is at issue”. The personal story of Tracy Snelling features in the newsletter, issue 3 of 3 (2014). On page 6, her “undignified death” is described by her husband, where, following a diagnosis of stomach cancer, she was “denied the choice to decide how and when she died”. This visually emotive story, including a

beautiful wedding photo taken shortly before Tracey died, clearly frames the organisations' objectives of *choice* and *dignity* as important to the end of life. DiD comment in an afterword to this story on page 7 that "Personal testimonies such as these are a fundamental part of the campaign" and they explain how, through the efforts of campaigning organisations, these stories are able to bring assisted death into the public consciousness. Dalton (2007:38) highlights the potential impact of this, claiming "testimonies and case studies provide valuable reinforcement to the more generalised messages directed at target institutions and the media". More of these personal narratives are analysed in section 7.4.

Explicit references to legal rights were made on page 22 of the newsletter, issue 3 of 3, detailing the Government response to a report published by the House of Commons Mental Capacity Act Committee in June 2014. This report found "vulnerable adults were not being fully protected or empowered to make decisions for themselves". Government response acknowledged the importance of "individual patients' rights and involvement in decision-making". The inclusion of this article in the newsletter serves to highlight a notion of *patients' rights* and illustrate how rights discourses can promote autonomous decision-making. The article also drew upon rights to critique the inadequacy of provision for vulnerable adults in the current decision-making process and, in doing so, demonstrated how this signifies the need for political change.

An understanding of rights as legal entitlements was also highlighted through another personal story under the heading "Protecting patient rights and DNR" on page 23 of the same newsletter. This feature illustrated how one patient was subject to a "Do Not Resuscitate" (DNR) order without her knowledge or consent. This individual's story was linked to Article 8 of the HRA 1998 through the breaching of her right to respect for a private and family life. Direct reference to the HRA Art 8 in this newsletter demonstrates that DiD, drawing upon national human rights instruments to support their position, do, on occasion, take what has generally been understood as a rights-based approach. However, this is used only when it can benefit and advance their arguments and this *strategic* use is more typical of *rights-framed* approaches (see *Figure 7.5*). This particular example was used with the intention of promoting Advance Decision-making as empowering and necessary to protect individual preferences and rights at the end of life. Using the power of the HRA 1998 to challenge a DNR order reveals a strategic use of rights that, in this context, serves the purpose of the organisation by raising awareness of Advanced Decisions.

The cartoon below also features in newsletter issue 3 of 3, on page 5. The intention is to motivate and mobilise supporters by suggesting “Pressure for change is building”. It illustrates how DiD invoke human rights and attempt to legitimate their aims by drawing on the credibility of the Human Rights Act 1998. The HRA is characterised as an indicator of justice used to weigh the arguments on assisted dying and help tip the scales in favour of change. The cartoon also highlights strong public support for legalisation of the Assisted Dying Bill 2014 that was formulated and proposed by Lord Falconer, through inclusion of the recently held and well-attended public demonstration outside Parliament to support change in law. The cartoon mocks the remaining politicians who refuse to acknowledge public opinion and the provisions of the HRA and respond accordingly to the mounting public and legal pressure.

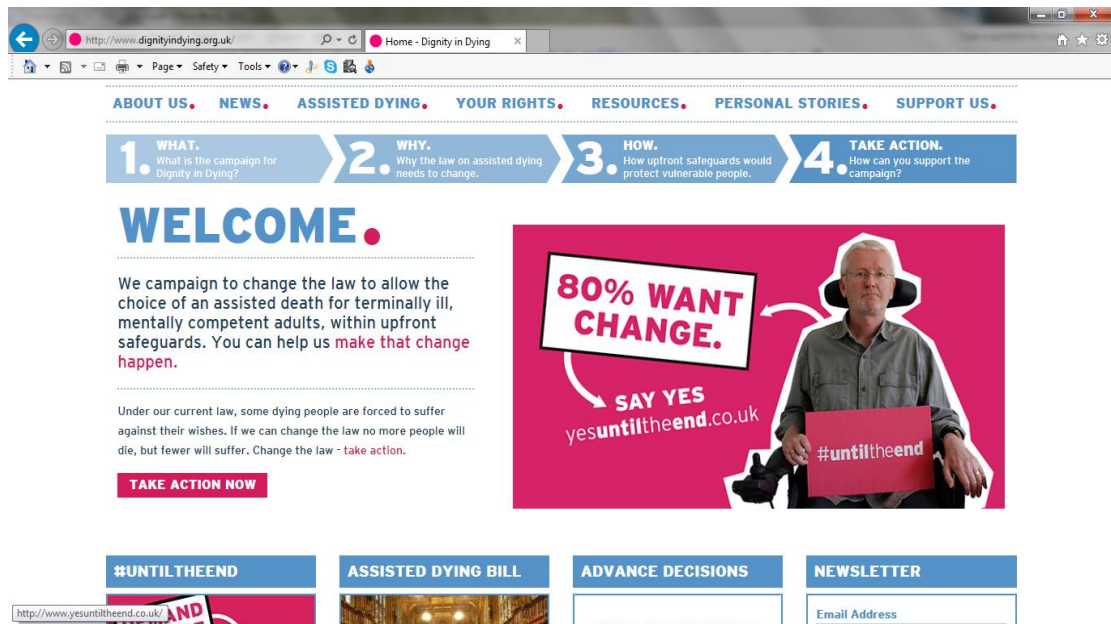
Figure 7.2 2014 Dignity in Dying “cartoon”, campaign newsletter, issue 3 of 3, p5



7.3.2 Website

The DiD website is comprehensive, informative and revised often. Since 2014 it has become more interactive to include access to social media sites Facebook and Twitter and the option to “Share” information. Below is a screenshot of their home page that reflects the style of their campaign shortly before the 2014 Assisted Dying Bill was debated in July in the House of Lords.

Figure 7.3. "Home" page Dignity in Dying website, June 2014



This colorful welcome page demonstrates examples of diagnostic, prognostic and motivational framing techniques as defined by Snow and Benford (2000). These techniques, used as a campaign tactic, serve to analyse the cause of the problem, motivate action and suggest a viable solution. In the above example, terminally ill adults are portrayed as victims of tragic circumstances who are suffering and unable to attain control over a dignified and good death due to the ambiguity and limitations of (inadequate) binding UK legislation and end of life provision. This position was supported by a number of contributions in the personal narratives analysed below, in which the current law was criticised as failing to meet the needs of the dying. Discursive strategies such as these function to place social actors and institutional practices in competition. Positioning seriously ill individuals as being trapped by unfortunate, and potentially undignified circumstances, highlights a right to die as a humane solution that enhances human dignity and individual liberty. The message is personalised through a thought-provoking image of a wheelchair-bound gentleman. This representation may have wide appeal, including to persons who are ill or incapacitated, which is indicative of a number

of DiD supporters. DiD highlight the distressing situation caused by actual or anticipated suffering at the end of life to indicate a dubious morality and intent of current institutions where “some dying people are forced to suffer against their wishes. If we can change the law, no more will die but fewer will suffer” (DiD a, 2014).

The problem of not permitting an assisted death is diagnosed as the current law, which forces people to *suffer* in the absence of provision for assisted death. The solution to the problem is clearly stated as a change in law and this is where the energy of the DiD campaign is directed. The assisted dying dilemma presented here is illustrative of Stammers (1999) social constructionist contribution referring to the relationship between human rights, power and social institutions. The NHS, as a UK institution, are representative of delivering the current medical model of end of life care. Law and policy dictate permitted actions and retain power to curtail or enhance liberty over end of life decision-making, while the dying represent those struggling for emancipatory change to self-determine the manner and timing of their own death. In this triadic relationship between the dying, law and policy and the NHS, the dying are portrayed as especially disempowered through their physical and emotional frailty. This highlights the poignancy of their cause.

Discourses used by DiD must convince their members or potential supporters that the aims of the organisation have relevance, can offer benefit to them, and are in their best interests (McInerney, 2000: 137). All mediated contributions are designed to inform and inspire, ultimately seeking to build a collective identity through a common desire for a *dignified* and *good* death and one that is not constrained by unbearable suffering or limited choice at the end of life. Building identity is an important part of the process through which individuals give meaning to their own experiences or transformation over time, and DiD capitalise upon this need (Della Porta and Diani, 2006:92). DiD use a *rights frame* to promote solidarity with the campaign. Dying well and experiencing a good death are common aspirations that may be compatible with contemporary community values, especially when articulated as a *right to die well* and *right to a good death*. Not all individuals will desire or value the option of assisted death, but all human beings, irrespective of their backgrounds and beliefs, would like to die well and achieve what, for them, is considered a good death. DiD frame the denial of choice and liberty at the end of life as unjust, especially with regard to rational adults. This accusation is accentuated by the experience of actual or anticipated suffering. The use of rights discourses

that promote choice and dignity at the end of life to achieve a good death and die well, is a particularly influential and persuasive campaign tactic with wide appeal.

Analysis of mediated communication over the period of study 2012-16 demonstrated that rights discourses have remained central to the organisation but the *scope* and *application* of rights, has at times been extended or different conceptions of rights brought forward. The newest addition to their website reviewed in May 2016 argued “We believe everybody has the right to a good death. Including the option of assisted dying for terminally ill, mentally competent adults” (DiD a, 2016). This recent shift in nuance suggests that a legal right to assisted death can help promote a *good* death, the importance of which was highlighted in section 2.2. In this way, the boundaries of a (hypothetical) right to die in the form of an assisted death have been extended even further to encompass a right to a good death. This inference is strengthened through development of a notion of a right, not only to a dignified death, but “[t]he right, when dying, to die well” (DiD b, 2016) articulated as part of the campaign aims for 2016. DiD have refined their interpretation of rights in relation to assisted death, presently expressed through the “right to a dignified death” and a “right to a good death” or the “right to die well”.

In addition, concepts of suffering, not usually associated with rights, are being engaged as part of the discourse on dying through idealised concepts of dignity and choice. In June, 2016, the “About us” page was yet again amended, introducing DiD as a “national campaign and membership organisation demanding greater choice and control to alleviate *suffering* at the end of life”. This indicated a potential shift at DiD away from *explicit* references to rights as the direction of the organisation began to focus more on the alleviation of suffering. Reasons for this are not apparent but may be related to defeat of the 2014 House of Lords Bill and 2015 House of Commons Bill. This finding demonstrates a strategic use of rights discourses in order to maximise the social context. The incorporation of rights discourses as a way to repackage the ideological underpinnings of the organisation and the foregrounding of rights to a greater or lesser extent at different times is indicative of rights-framed approaches (RFAs) proposed by Miller (2010) in Chapter 3. Rights discourses are applied, or in the case of DiD, *prioritised* in *specific contexts* where they are considered for a variety of reasons to be *strategically advantageous* (Miller, 2010).

Examining *how* and *why* rights discourses are adopted, or disregarded, by campaigning organisations in relation to particular social contexts can contribute towards understanding the “social life of rights” as defined by Wilson (2006). However, in relation to end of life, the reasons for this are not immediately obvious. Moving away from a rights frame could have to do with the ways in which the HRA 1998 may be beginning to lose traction in the current UK political climate. There is certainly a reduction in the number of cases taken to Strasbourg and number of findings against the UK is lower (Hoffman and Rowe, 2010:35). This may be argued as due to the development of UK equality and anti-discrimination legislation that encourages compliance with the HRA 1998 and thus negates the necessity of further intervention in human rights cases. The HRA 1998 is itself, at present, a contentious instrument. The current Conservative government have sought to reduce the influence of the HRA 1998 by not giving it constitutional status and have instead proposed replacing it with a Bill of Rights. The HRA 1998 has also lost popularity with the UK public to judge by the negative tabloid press where it is perceived as being abused by “undesirable groups such as asylum seekers” (Sweeney, 2010:76).

7.4 Voices within Dignity in Dying

Dignity in Dying utilise a variety of voices within the organisation with the intention of validating their objectives, creating impact, resonating with target audiences and mobilising public support. This section examines the voices of Patrons and members of the public through their personal narratives to assess *how* and *for what purposes* they draw upon rights discourses and *the extent* to which this is used to enhance their arguments or describe their experiences.

7.4.1 Patrons

Many of the DiD Patrons are celebrity or influential figures and they serve two important functions. Firstly, they contribute a large amount of essential funding as high net worth individuals. Secondly, Patrons can endorse the aims and objectives of the organisation. Their purpose is to engage public support and extend the reach of DiD through strategically framing and promoting a persuasive narrative of dying. Benford and Snow (2000:619) suggest that adopting a rights frame can be advantageous in transforming perceptions of what is just or unjust and in proposing generic values that may be compatible with moral systems. DiD utilise this frame encompassing a notion of individual liberty and respect for human dignity to resonate with contemporary aspirations, which for some individuals extend to determining the

manner and timing of death. In total, there are statements from 68 patrons on the website representing a wide variety of social and political backgrounds. These include actors Sir Patrick Stewart, Hugh Grant, and Kim Cattrall, Falkland Islands hero Simon Weston OBE, and entrepreneur Peter Jones together with a range of medical doctors, lawyers, political and religious figures. The voices of Patrons are quoted on the DiD “Home” page (accessed 13.05.14).

The majority of Patron contributions grounded their understanding of a right to die in the notion of individual liberty. Professor Anthony Grayling, as a humanist and scholar, asserted as fundamental “Decisions about the timing and manner of death belong to the individual as a human right” or popular actor Hugh Grant, “I strongly believe that-with the right provisos and controls-a person should have a right to end their life with dignity if that is their wish” (DiD d, 2014). These statements are underpinned by concepts of *choice* and *dignity* that were also evident in Professor Sir Graeme Catto’s comprehensive and eloquent argument involving “dignity” “right” “choice” “control”. This mirrors the language used by DiD. In addition, it reflects his own medical background and aligns his position with other members of the medical profession. His comment linked compassion with rights. This strategic use of language invites support from doctors, who on the basis of *compassion* could perhaps be persuaded to extend their current practice and assist requested death out of respect for the *rights* of patients. He argued

We do see patients who die without dignity and without the compassion that we should be providing. There are many doctors, like me, who believe that assisted dying should be a right for our patients. As more have the courage to speak out, the more we can work towards giving choice and control to the patient (DiD d, 2014).

As former Chair of DiD, and former President of the General Medical Council, Sir Graeme Catto’s contribution is both tactically clever and important. His perspective associated the esteemed concepts of dignity and compassion with a rights approach, articulated as choice and control.

Some statements from Patrons referred to rights as legal entitlements and critiqued the lack of current provision, for example Sir Patrick Stewart who tactically endorsed “control” to mirror the vision of the organisation “We have no control over how we arrive in the world, but at the end of life we should have legal control over how we leave it” (DiD d, 2014). This comment stimulates political deliberation on the issue and DiD tactically utilised this alongside the contribution from Patron Dame Elizabeth Hoodless DBE to draw the assisted dying debate into

parallel with other ethical dilemmas that have already been debated upon with ensuing legislative change. She advised “Respect for people’s freedom to choose is reflected in our abortion laws and civil partnerships. Respect for people’s choice on the ending of their life should be included too” (DiD d, 2014).

The contributions of Patrons supported a broad liberal ideology. This was evident in their statements through their use of “virtue words” (Lee and Lee, 1972:23). The findings of this analysis revealed virtue words to be grounded in interpretations of rights. Many of the arguments invoked rights discourses that included “rights”, “choice”, “control”, “freedoms” “suffering” and “dignity”. Using the voices of Patrons as a campaign tactic to foreground different aspects of rights, for the purposes of resonating with target audiences, is characteristic of RFAs. Through these voices, a right to die could appeal to individuals accessing the website who may not yet be sympathetic to the cause, but may be sympathetic to the values, and discourses used to express those values, by celebrity figures, whom they view as representative and/ or who are held in high esteem.

7.4.2 Public narratives

On their website, in the section headed “Personal stories”, Dignity in Dying strategically chronicle the narratives of individuals who are living with a serious condition, are dying or have been bereaved. Wilson and Brown (2009:10) argue “Arousing sympathy and awakening moral qualms, and connecting them to real or imagined self-interest, appears to be the proven method for the realization of human rights”. Narratives resonate because dying is a universal phenomenon. All are susceptible to serious illness. The purpose of these individual stories is to engage readers on a personal level, enhance proximity to the issue and potentially transform public perceptions on death and dying. Personal experiences highlight circumstances of human frailty and vulnerability in the dying process. Graphic details of suffering and traumatic death in the personal narratives are used to motivate those accessing the website by invoking sympathy or empathy with the plight of the dying. Episodic framing that describes individual pain and symptoms is a powerful strategy that heightens proximity to the personal experience and provokes a response from the reader.

Each of the 36 personal stories selected from London and the South East region⁶⁵ represents an undeniably real and individual lived experience and this has a vivid appeal. Analysis of the language used to describe the personal stories revealed frames of “choice” “dignity” “suffering” and “rights” that provided an insight of *how* the issue of assisted death was positioned, thought about and given meaning. A tag cloud was generated initially using NVivo10 software to provide an overview of the most frequently used words appearing in these personal narratives. These were then coded under different nodes and analysed in context. Those most frequently occurring and relevant to the debate are explored in detail below.

Figure 7.4: Tag cloud to show word frequency in Dignity in Dying personal stories (DiD, 2014).



⁶⁵ Further research could include comparative analysis of attitudes towards death and dying and how these are expressed based upon the attributes of geographic location and gender. Focus on these indicators to address the discourses used by samples of the UK population, and reflect the thoughts of different groups of individuals towards end of life, could build upon theories of healthcare inequalities.

take taken terminally think three **time** told treatment want
wanted weeks well went wife wish wishes without year **years**

Suffering

There were 311 references to the word “suffering” but different forms of the verb also included “suffer” (114) and “suffered” (50) that totalled 475 references across 36 personal stories making this the most commonly featured issue. The frequency with which suffering was mentioned initially suggested three things. Firstly, that concepts of suffering are particularly important at the end of life to dying people and their family members. Secondly, that suffering is a term used and understood by members of the public to reflect their concerns, and thirdly, that DiD strategically recognised the appeal of the articulated experience of suffering to both a public and healthcare professional audience. The literature in Chapter 2 showed that suffering often features as a generic or ambiguous term involving a tacit understanding of meaning but one which also allows for subjective and relative interpretations. Reading the personal narratives, it became clear that the phenomenon of suffering is complex and understandings of suffering were enhanced using the detail in their own words. The personal narratives analysed in this case study have informed the concept of suffering at the end of life and provided a contribution to knowledge on the experience of suffering through selected coding under three different nodes. These nodes were classified as: 1) emotional anguish; 2) physical symptoms; 3) incapacity and decline.

The following excerpts illustrated emotional anguish

She was broken hearted and in a living hell while she waited to die... in a permanent state of existential suffering and some physical pain – a state worse than death (Penelope Duck, 2013).

The option of assisted dying would give me such comfort; to know that I didn’t have to go on suffering forever, or have to take measures to end my life in another way (Lesley Evans, 2013).

Emotional anguish associated with dying is infrequently addressed, but evidently present. In these personal narratives, under the node “emotional anguish” a selection of words coded included “dread, devastating, horrible, frustrating, doomed, broken-hearted, damaged, harrowing, terrible, agony, grieving, afraid, sadness”. This highlighted the psychological component of suffering associated with life limiting illness in a group of individuals who are especially vulnerable in ways that are perhaps not apparent, visible, measurable or greatly

spoken about. In society, issues of mental health and personal emotions are less frequently discussed. These are, or were, commonly considered “taboo”, and this finding reflects an area neglected by healthcare professionals. The emotional and psychological anguish associated with dying may not be prioritised because healthcare professionals are under equipped or lack resources to address and support these issues. However, personal stories that foreground these issues and openly describe emotional anguish may resonate with the dying, their families or grieving individuals who are reading and experiencing them.

There were many examples coded under “physical symptoms” as an element of suffering. Dr Anne Turner, who chose to end her life at the Swiss Clinic Dignitas shared her experience,

I am finding walking, speaking and swallowing difficult. I have had a series of nasty falls. I broke my wrist twice and thumb once earlier last year and seemed to spend the early half of the year in plaster and waiting for hours in out-patients (Dr Anne Turner, 2007).

In contrast to emotional anguish, pain and physical symptoms are often visible, easily measurable, and socially acceptable to speak about. Many of these can be alleviated through medical intervention, the outcomes of which can be studied and monitored. Pain is a concept that has usually been experienced by all human beings and the memory of a painful incident may trigger the desire to avoid this in future. In the context of suffering, the individual narratives described experiencing one or more of the following physical symptoms in different degrees:

losing the power to communicate; difficulty or failure of breathing muscles; being fed through a tube; nausea and vomiting; affected speech and movement; physical pain; double incontinence; losing the use of hands, legs and arms; bedsores; muscle spasms; nasty falls, and broken bones.

The third node “incapacity and decline” combined the above elements to describe the mental and physical suffering associated with multiple losses during long-term or progressive illness. The narrative of Nicky Dalladay (2013) clearly illustrated the reciprocal relationship between his physical and mental suffering, “Every time another bit of my body stops functioning properly I have to go through a grieving process, so I liken it to a form of bereavement”. For some people, this process could involve a long, slow demise necessitating surgical operations, frequent medical appointments and becoming housebound or reliant on carers as the condition deteriorates. Chris Lerner’s ex-wife Allyson Lee experienced this type of suffering. It was significant enough to prompt her to travel to Dignitas to end her life in November 2010. Chris (2010) described how “In the last 10 years her MS progressed, leaving her housebound, doubly incontinent, distressed by constant muscle spasms and reliant on carers: and with no

hope of her health improving". A similar account of Pam Baker was written by her son Patrick (2013),

As her cancer progressed it had increasingly debilitating effects: first the paralysis of her legs, then the increasing deterioration of her speech, vision and hearing. In the final period of her life she made it clear that she wished to die; but her GP was not prepared to discuss ending her life.

Suffering, as a concept usually distinct from rights, is increasingly becoming associated with arguments supporting the right to an assisted death through rights discourses that involve respect for human dignity and a desire to avoid an undignified death. The experience of individual suffering in the above accounts clearly described the indignity associated with serious or terminal illness, not solely through painful symptoms and incapacity, but also through emotional anguish causing distress and the perception of losing dignity. Concepts of dignity and their connection with suffering are examined further in the following chapter through focus group discussion.

Choice

When "choice" was coded as a singular word, it appeared as the eighth most frequently used word in the personal narratives.⁶⁶ However, when other words associated with choice: "option", "control", "choose", "wish", "wishes" were coded at this node, there were 457 references in total, making this the second largest category after suffering. All references to "choice" were used in the context of personal liberty, and choice as reflecting decisional autonomy. "Control" was linked either to human agency whereby a person retains control over their bodily integrity in their current situation, or to the administration of drugs controlling pain and symptoms. Reading the personal narratives, a sense of maintaining control and choice over one's options was perceived as important to affirm identity and individual personhood. These narratives grounded the vision of DiD in human experience. This was illustrated by the account of Joyce Skerrett referring to her husband's death from oesophageal cancer,

He begged the doctor to allow him to die, he had suffered enough. If we had known it was possible for him to be assisted to die in Switzerland he would have chosen to do so. As it was, he suffered 8 more weeks of agony. It is so important that we are all given the choice to die in these circumstances.

⁶⁶ The most frequently occurring singular word was *life*. It featured a surprising 408 times in the personal accounts of dying! Life references were made in relation to personal experiences, general thoughts on life, the taking and ending of life, and in connection with the phrases "quality of life" and "life expectancy". Life quality, although frequently alluded to, was not specifically defined, or discussed in-depth, in the personal stories.

Individual choice is a desirable characteristic, increasingly respected in a contemporary social context and is, to a degree, reflected in current healthcare policy. However, realisation of individual choice at the end of life fundamentally conflicts with the paternalist medical model of care. In response to the study by Auerbach, (2001) cited in section 2.2.3 that the majority of dying individuals would encourage collaboration and information sharing with their doctors but would not wish for decisional control at the end of life, one contribution from the personal narratives shared

I would like there to be a more open and honest discussion with medical professionals, patients and their families about the dying process. This would mean that decisions about end of life care came from the patient, where possible, rather than the doctors (Liz Silvester, 2013).

A number of personal stories linked choice at the end of life with their desire to see a change in the law, perceiving the current legal system as restrictive of individual liberty. Typical examples of this included Peter Chesterfield (2005) who argued that the current law is morally unacceptable as it forces individuals to suffer in the dying process

...the law prevents a doctor from helping me to die at my request... Only with a law that allows a patient to have a choice and to express this within a properly safeguarded system will we allow true human justice and dignity.

And an 18 year old male, with the gene for Huntingdon's Chorea who chided

The law as it stands is simply not fair; assisted dying needs to be made law to protect the dignity of those who live life with pride and want to face death in the manner that they choose. With such a law, people such as myself won't be forced to go through a slow decline with complete loss of dignity (Josh Cook, 2013).

Rights

References to rights in the personal narratives were predominantly used in the context of articulating the right to die and the right to choose. They were also expressed in conjunction with "right" as referring to timing, position, and right versus wrong, as in Joanne's (2013) contribution that uses rights in two different contexts, "I am a believer in giving people the right to end their life early if they are terminally ill and are one hundred percent certain that it is right for them to do so". There were 181 explicit references to the word "right" in the personal stories selected and these were used in different contexts. Personal narratives making *explicit* references to concepts of included the following

Allyson was very clear that it was her right to do what she wanted with her life (Chris Lerner, 2013).

To die with dignity should be everybody's right (Dr Anne Turner, 2013).

These expressions of rights attempted to justify the choice of assisted death grounded in free will through the inherently rational nature of human beings, especially in the face of serious, debilitating illness. Both contributions position a right to die as a fundamental, individual liberty right.

Human rights discourses used in the public narratives, in contrast to Patron support and the dominant rhetoric of DiD, demonstrated relatively little consideration of rights as legal entitlements, although some patients were aware of the current limitations of the law. This was expressed clearly in the comprehensive contribution by Jane McDonald who died from Multiple Sclerosis and bone cancer in August 2009,

As a former nurse I am aware that despite the best medical care and the finest hospices, there is a chance of dying in pain and certainly in distress, with a loss of my personal dignity. I would like the opportunity to choose the time and place of my death if life becomes unbearable. To do this I would need the help of a doctor who would be open to prosecution by offering help. The law needs to be changed so that this simple humanitarian assistance can be offered to those who wish for it, this should be within the law, provided that appropriate safeguards are in place.

When an initial query was run using NVivo10, the term "right" appeared as only the eighth most frequently occurring word. The apparent lack of references to rights understood as *human rights* in the public narratives seemed to dispute the hypothesis that rights were central to the end of life policy and debate on assisted death. Analysis of the personal narratives suggested that not all voices within the organisation explicitly articulated rights or defined their experiences through rights discourses. Personal stories referred less to understandings of rights compared to other actors in the organisation and with information presented through mediated communication. Analysis of the themes running throughout the personal stories revealed that "choice" was referenced 54 times in 31 sources and "suffering" was referenced 49 times in 29 sources, compared to "dignity" that only featured 22 times in 15 sources and "rights" that occurred 16 times in 11 sources.

The main reasons suggested for this unexpectedly low reference to rights is that members of the public through their personal accounts demonstrated that they were not familiar or

comfortable with *explicitly* using *rights*. Members of the public could also have a very limited understanding of human rights *per se*. Instead, their stories focused on their own experience of illness, their symptoms and the suffering they endured as part of their illness. Arguments were largely validated through their phenomenological experiences using everyday language such as pain, suffering and choice. These concepts, which typified the discourse used by members of the public, are characterised as having localised and immediate meanings (Christie and Martin, 2007: 6). Although the personal narratives, compared to other voices in the organisation, showed less engagement with their predicament in terms of rights, an *implied* or *implicit* understanding of rights discourses was revealed in a number of personal accounts. These *implied* associations with rights informing end of life primarily included individual choice and a desire to alleviate suffering in order to maintain human dignity. The findings of the data also confirmed that singular components of rights, including choice and control, were valued so that rights were implicitly understood to promote and support human self-determination and free will as a natural desire.

Dignity

In the word frequency query, “dignity” occurred 134 times, but was coded infrequently at nodes because it was mostly used in the context of referring to the organisation Dignity in Dying. The lack of reference to human dignity in the selected narratives was surprising. It was a significant contrast to the language used generally by Dignity in Dying to support their objectives and to earlier findings in the research, where the concept of dignity featured prominently in current UK healthcare policy and was also discussed during the later House of Lords debates. The minimal references to dignity expressed in only 15 out of 36 personal stories, were mostly ambiguous, and, when not used to refer to the organisation Dignity in Dying, were used and understood *implicitly* as part of a rights discourse citing respect for the maintenance of inherent personal dignity. Although the narratives did not articulate dignity and indignity as such, it is suggested that their comprehensive experiences of suffering and focus on painful symptoms, did encompass aspects of this. As proposed above, the lived experience of suffering indirectly relates to public perceptions of dignity and is frequently used to describe what is regarded as an undignified situation at the end of life. In addition, the desire for an assisted death in order to relieve unbearable suffering *implies* a means to being able to achieve a more dignified death. In this way, concepts of suffering and dignity are being spoken of, and woven together, through an understanding of human rights.

Critical summary

Analysis of the individual narratives that prioritised *choice*, and *dignity* through the *relief of suffering*, has demonstrated how a sample of the public has interpreted and articulated their understanding of rights within the context of death and dying. These particular frames resonate across a broad spectrum of target audiences. Narratives are crucial to defining the terms of the end of life debate. They serve to construct a shared meaning and social identity and, to an extent, the findings have revealed that rights discourses are understood as important at the end of life. Readers can identify with these narratives in relation to their own experiences or that of loved ones, enhancing Turner's notion of collective sympathy discussed earlier. In some of the personal stories, the focus was not on rights but the distressing symptoms and state of suffering where support for a right to die was generated through evoking a common human sympathy at the distressing circumstances endured by some dying individuals. In the context of a campaigning organisation, the personal stories that foreground rights to a greater or lesser extent explains how rights discourses may be adopted or disregarded as a strategy to suit the objectives of the organisation and the current social or political context. This is indicative of RFAs as proposed by Miller (2010).

Conclusion

This chapter has provided an insight into the strategies of Dignity in Dying as a national organisation campaigning to legalise assisted death. They are unique on the basis of their historic foundations. The organisation has campaigned on a single issue over a period of 81 years and operated in a social environment that has seen many changes during this time. The original VES was established in 1935 and a right to assisted death, or voluntary euthanasia as it was termed, was initially defended as an act of mercy on the basis of a concern with dying terribly and in pain. At the outset, the organisation showed some awareness of rights when it was argued by Killick Millard (1931) that "incurables" should be permitted voluntary active euthanasia as an "elementary human right". However, rights were not articulated explicitly in the aims or ethos of the organisation, nor discussed further at this time.

The case study findings suggested that rights discourses are more widely used by the organisation in a contemporary context and have become central to defining the terms of the end of life debate. An increased life expectancy, together with the ability of modern medicine to prolong and postpone the dying experience, has revealed unbearable suffering at the end of

life as a reality in the typical experience of death and dying. Understanding rights in the context of increasing healthcare consumerism, and highlighting the poignant inequalities in healthcare policy and legal statute where “some dying people are forced to suffer against their wishes” issues a challenge to medical paternalism and argues that assisted dying is a credible alternative, or at least an additional option, to the mainstream medical model (DiD b, 2016). As a result of changes evident in the late modern dying trajectory, the apparent proliferation of rights discourses, and the activities of campaigning organisations, assisted dying has been redefined as an individual right to die. This case study analysis has illustrated how, when, for what purposes, and to what extent, rights discourses have come to be utilised to interpret and articulate the complex issue of requested death and embed rights in this context.

Responding to the call by Miller (2010) to further develop understandings of rights strategies outside traditional rights-based approaches, the data from this chapter largely corroborates that DiD did adopt a rights-framed approach (RFA, as defined by Miller, 2010). As an organisation campaigning on one distinct and peculiar issue, DiD are indicative of how RFAs continue to emerge in other sectors and contexts. Within an end of life context, rights discourses were used *strategically* and *specifically* by DiD as a key part of their campaign to legalise assisted death. The research data demonstrated that, particularly in the campaign period leading up to the 2014 House of Lords debate, the activities of Dignity in Dying reflected the social context and employed rights discourses in conjunction with their own purposes. As a specific strategy, this was intended to resonate with target audiences, namely, members of the public and political figures who were soon to debate the issue in the House of Lords.

The concept of framing is one of the six key dimensions of a RFA (Miller, 2010:925). Since 2006, DiD centralised the value of human *dignity*, both through the name of the organisation and more recently through their aim of a dignified death, expressed as a “right to a dignified death”, a “right to die well” and the “right to a good death. *Choice* was also expressed and foregrounded through the vision of the organisation in order to enhance their objectives of “choice”, “access”, and “control” at the end of life. The strategic use of a rights frame linking notions of choice and dignity understood as rights, was evident through analysis of mediated communication, the voices of Patrons and personal narratives. This *instrumental* use of rights discourses was used to enhance arguments for permitting individuals to die according to their own values and beliefs.

The application of a RFA represents a *tool*, used to *serve* the official approach of DiD. In the case of DiD, this was not necessarily defined by a normative understanding of human rights frameworks but rather reflected and supported the liberal foundations of the organisation that highlight individual liberty to determine the manner and timing of death. Through the desire for a good death, DiD offered a new basis for a collective identity based on a universally aspirational understanding of rights that challenged the indignity of dying, instead promoting the option of dying well. In light of Miller’s (2010) contribution, the case study of DiD supported and built upon her conclusion that there are different ways of using rights. It confirmed that a “one size fits all” label cannot be applied. The case study findings are presented below to illustrate the ways in which DiD utilised a rights-framed approach in the context of their campaign to legalise assisted dying. This table has been developed from Miller’s (2010:924) original table with her permission.

Figure 7.5: Illustrating Dignity in Dying’s use of a rights-framed approach

<i>Rights-framed approaches as developed by Miller (2010)</i>	<i>Example of a rights-framed approach demonstrated by Dignity in Dying</i>
Used as a tool to serve the official approach	Contemporary, official approach emphasises dignity and liberty “We believe that everyone has the right to a dignified death”. Realised through “choice, access and control”
Is driven by NGO policy	Policy goals to legalise assisted death (right to die) for mentally competent, terminally ill adults
Starts from ideological base, then strategically repackages beliefs and ideas through a human rights frame to potentially: motivate/mobilise collective action; demobilise antagonists; legitimate	Liberal ideological base (more apparent in contemporary context). Repackages right to choose and right to dignified death to mobilise public. Demobilises antagonists and legitimises actions through desire to

action; advance own beliefs; transform terms of the debate, and 'fit' institutional venues	alleviate suffering. Transforms debate through belief that everyone has a right to a good death and to die well. Resonates with healthcare policy and institutions through emphasis on dignity and patient participation
Will strategically utilise the power of the idea of universal human rights to motivate others (activists and campaign targets)	Dignity centralised within the organisation since 2006. Reflecting foundational position on rights, inherent and universal dignity used strategically to motivate <i>all</i> members of public and potential political allies
Strategic priorities may make references to ideas of human rights (and less frequently international standards) but this is not required	Strategic priorities use Patrons and personal narratives to articulate their understandings of rights and draw debate into parallel with other complex dilemmas. No direct references to international human rights standards, for example, the right to life or the right to privacy
Only appeals to ideas of rights when considered to be strategically advantageous to specific campaign contexts	Rights discourses most emphatic at the time of the 2014 House of Lords debate, particularly evident in campaign newsletter issue 3 of 3
Only on occasion and when beneficial will cite specific human rights language, covenants or agreements	Provisions in the HRA 1998 cited in campaign newsletter issue 3 of 3 to highlight patients' rights and promote advance decision-making

The case study analysis of DiD demonstrated some common findings with the House of Lords debates in respect of the language used and the ways in which rights discourses were adopted and given meaning. Data from both stages of the research revealed a historic variation in language, and provided examples where different understandings and interpretations of human rights were evident and had been developed to a greater or lesser extent. These findings suggest that rights discourses have become central to, and are currently being used to

define the end of life debate and policy on assisted death, but in ways that are complex and warrant further sociological exploration.

The following chapter examines the views of selected members of the public to hear the language with which they articulate their concerns and thoughts on death and dying, and how they understand a right to die in the current social context. The reach and impact of rights discourses can be indicated, in part, through hearing the perceptions of members of the public as they contemplate the issue of assisted death. This could suggest how widely or effectively rights discourses are permeating the public sphere, and to what extent they are being used to negotiate issues at the end of life.

CHAPTER 8

Focus group discussions with Death Café participants

The purpose of this chapter is to analyse *how* focus group participants used and understood human rights discourses when considering issues at the end of life. This chapter will examine the ways in which, and to what extent, a previously unexplored subject group adopted rights discourses to discuss death and dying, independent of any apparent or organisational purpose. The participants represented a London-based sample of members of the public associated with Death Café, Hampstead who identified themselves as having a specific interest in speaking about end of life, evidenced by their attendance at Death Café. This research is the first to analyse these new voices through three focus group discussions conducted at the Café Rouge, Hampstead in September 2014, October 2014, and February 2015. Participants included professional, educated individuals living in a relatively affluent area and each group comprised both males and females of a varied age range. Although this was not a truly representative sample of the public and the findings are not definitive, analysis of their discussions did illuminate the language with which some members of the public conveyed their concerns and

values on end of life. Such voices act as a supplementary finding, constituting part of a wider narrative informing the debate in a current context.

This chapter is divided into two parts. The first section begins by introducing participants' responses when they were directly asked what they understood by having a *right to* something. Subsections then examine, more specifically, predetermined concepts identified as important from the findings of the earlier stages of the research. These concepts, including dignity, liberty, capacity, and suffering were also of interest to focus group participants and were mostly grounded in, or associated with, human rights discourses. However, they may not have been explicitly articulated or interpreted as such. The second section examines alternative approaches to the end of life expressed by participants in light of their religious beliefs and cultural backgrounds. The chapter concludes with an analysis of how central rights discourses were to participant discussion on end of life and the extent to which this informed their perceptions of a good death.

8.1 Understanding rights

Approximately half way through each discussion I asked "So what do you understand by a right to die, what is a *right to* something?" This question was met with complete silence in all three groups! Despite having allowed participants time to become comfortable with each other, generate good discussion and share their thoughts and experiences on topics that included dignity, choice and suffering, this question clearly proved awkward. Non-verbal communication indicating this included the raising of eyebrows, frowning, looking away, audible sighs, sniffing and intake of breath, murmurs, slight raising of shoulders and shifting of position. The only direct and immediate response came from a 30 year old female in the first focus group who touched upon the essence of rights from the perspective of individual liberty, "It comes back to the issue of having control".

Participants were noticeably uncomfortable with this direct question, so I prompted on each occasion "Do you think people should have a right to ask for assistance to die?" This question did initiate conversation. There was a general murmur of agreement and nodding of heads but rather than speaking in-depth on rights, each of the discussions moved quickly in other directions. This finding was key to the research data that certainly demonstrated how

members of the public had difficulty relating to *rights*, as such and did not seem to contemplate rights *explicitly* in this context. All participants appeared unfamiliar with the concept of having a *right to die* and were reluctant to engage further in discussion. The sole participant who articulated a notion of rights directly spoke about a “right to choose” in relation to her desire for a pain-free death,

I would like the right to choose should I get cancer, which I don't believe I will. I would like to have the morphine in my hand, or to have someone I could trust...and even though I want to have a conscious death, I don't know how I am going to respond to severe pain (Female, aged 59).

This conjunction of a right to choose has been evident throughout the history of Dignity in Dying and has surfaced more recently in the later House of Lords debates and healthcare policy as choice becomes an increasingly esteemed concept. Although no other comments spoke of a right to choose directly, this idea was obviously inherent and *implied* throughout the discussions that emphasised choice as an expression of individual liberty.

During the focus groups, a number of responses recognised the constructed nature of a right to die as they acknowledged variations on attitudes towards death and dying that were time and context specific. One indicative example argued

You could say it's the baby boomers belief that they can decide how they want to live, they can decide how they want to die, they can have a baby, birth control and they can have assisted dying if they want to (Female aged 63).

This “baby boomers belief” highlighted the extent to which individual choice in contemporary UK society has become an idealised and accepted concept. Interestingly, this comment illustrated how belief in personal liberty was not defined or limited by traditional frameworks or institutionalised norms, corroborating the earlier observation that the UK is becoming more secular and less community oriented. Instead, it supported a notion of unconditional liberty, allowing “baby boomers” to make unrestricted decisions in complex and personal dilemmas, including matters of life and death. Another comment raised cultural, geographical and class differences to show how particular discourses could develop in relation to a social context,

I think the issue around life and death is still taboo. People find it very hard to deal with...in other countries it's not even an issue. In Greece where I come from I don't even think people...if we die, it's an end to suffering, especially in rural places, so I think the right to die is kind of a middle class construct (Female, aged 36).

When speaking directly about a right to die, most group participants referenced this in relation to a legal context, as in *having a right* and being *entitled to* something. One could say that their

understanding of an explicitly articulated right to die was reflective of a legal positivist approach to rights. There was, however, a noticeable lack of knowledge over the current legal status of assisting a suicide suggesting participants had not explored these options in detail. Perhaps they had no need or interest in doing so. In each of the group discussions, I briefly explained the legally permitted options at the end of life and outlined the most recently proposed House of Lords Bill. Armed with this information, opinion was divided on whether legislation would be a definitive course of action. One comment that indicated faith in the role of the law argued “somebody’s got to decide, you can’t have it not enshrined in law or everybody would be bumping everybody off!” (Male, aged 60). Another person continued this discussion to question the limitations of the law, in particular, the ability of institutions to monitor and implement a (hypothetical) right to die fairly, “Once a law is passed who is going to check whether this is their real choice or if it’s uncertain because it’s for their will or money?” (Female, aged 66). This was an insightful observation and one that was also raised as a concern in the more recent House of Lords debates in opposition to legalising assisted death. From a liberal perspective, state responsibility entails the regulation and enforcing of moral conduct to protect citizens from harm. However, establishing legality does not prevent abuse, and, even where there are stringent safeguards in place, the extent of “real choice” can remain ambiguous.

In one group, rights were generally understood as legal entitlements and here participants were especially concerned that the current prohibition on assisted death was forcing desperate individuals to take measures to end their own life and how this could have a detrimental impact on other people. One person commented

I think it’s far better to do it in controlled conditions than it is for somebody to jump off a building or in front of a bus or train. That is cruel on anybody else. At least in your own environment you’re not traumatising anyone else (Male, aged 65).

In contrast to the House of Lords debates where it was argued that legalisation of assisted death may potentially lead to abuse of the vulnerable, elderly and disabled who may be subject to assisted death without their consent, this remark expressed concern for not legalising an assisted death through fears for the direct and immediate consequences upon those witnessing a suicide. Individuals do not exist in isolation. Their death will impact upon other members of the community and the impact of watching the suicide of an individual may be traumatic and distressing. Assisted death, legally permitted within a controlled environment, enables dying individuals to determine the timing and conditions of their death with the possibility of loved ones being present. This was argued as less traumatic than

sudden, and desperate, actions impacting upon unrelated members of society. This contribution demonstrated some similarity to the argument of Diane Pretty in 2002 when she petitioned the court citing violation of Article 8 of the HRA 1998 claiming that ending her life was a private matter that ought to be free from state interference. There was no direct reference to the right to a private and family life in the focus groups, but in the same way that there was an evident respect for personal choice in the discussions, privacy was also valued.

All three focus groups were hesitant and unsure how to explain their attitudes towards a right to die and to elaborate upon their positions on rights in general. Despite the repeated question, their minimal responses suggested that for them, there was no apparent benefit, social, legal or political in using rights discourses explicitly in the context of death and dying which may explain the ambivalence. Although participants were used to sharing their own personal experiences and emotions in a group discussion, they may not be familiar with, or comfortable, speaking specifically in terms of rights in an end of life context. Focus group participants, in a similar manner to the personal narratives on the Dignity in Dying website, drew upon, and prioritised, their life experiences rather than thinking about dying from an intellectual or conceptual perspective. This may not negate the importance of rights as a plausible basis from which to debate the end of life, or dispute the essence of rights, but may be due to lack of understanding or familiarity with this discourse.

The idea of having a *right to die* in its literal sense was completely dismissed on a single occasion. This person who openly shared her spiritual beliefs and did not speak English as her first language observed “well we will die, so there’s not a right” (Female, aged 66). This critique was similar to that of Lord Tebbit in the House of Lords (2014, col 788) who argued “We do not have that right; we have only the capacity to do it”, and the question posed by Scolding (2011) in Chapter 1 “how can a right to something that inevitably happens to all of us suddenly arise?” These arguments are critical of a rights label. They take issue with a literal notion of rights and dispute the validity of rights discourses in relation to the end of life. Instead, these comments emphasise the natural and universal reality of death. This type of critique that totally rejects the application of rights to the end of life debate is a rare example. Additional participant contributions that did not support a rights approach from a religious or cultural perspective, are considered in section 8.2.

8.1.1 Dignity

In each focus group, I began the discussion by circulating the following quote typed on a piece of A4 paper: “I like to think that I have lived my life with dignity and I would like to be able to die with dignity” (Lisa Cooke, 2013). Participants were then asked directly “What does dignity mean to you?” At this stage of the research, I had corroborated dignity as an important but poorly theorised and ambiguous concept. Dignity constituted an essential component of human rights (Chapter 3), it was highly regarded in healthcare policy (Chapter 5), it was referred to in the historical debates (Chapter 6) and foregrounded in the campaign rhetoric and objectives of Dignity in Dying (Chapter 7). On this basis, I prioritised further exploration of the public perception of human dignity. Surprisingly, and in contrast to the direct question on rights, there was an immediate and enthusiastic level of engagement with the concept of dignity across all group discussions. Participant responses demonstrated that dignity in an end of life context was highly valued. In each group discussion, participants were conscious of the division between physical manifestations and the emotional/ psychological components of dignity. They identified concepts of both inherent human dignity and bestowed dignity through the relationship with others in a social context. The two are not mutually exclusive and focus groups supported the position of Jacobsen (2007) in section 3.1.1 who argued that dignity is a characteristic primarily residing in individuals but may then be earned, bestowed or diminished through social interaction.

Inherent dignity encompassing autonomy and free will was typically expressed in the following comments as

...control over your own bodily functions, maybe at the second level, autonomy of movement and will, whether that be assisted or not, but being able to go somewhere and do it if you want. Those are the two main things (Female, aged 50).

Dignity is being able to take care of yourself and feel comfortable with it (Female, aged 67).

I believe it's the ability to live according to the principles of one's mind...if I was in a situation where my mind was damaged, if I was to be resuscitated then don't resuscitate because it wouldn't be me (Female, aged 30).

These perceptions of inherent dignity assume a relationship between dignity and autonomy. Review of the literature confirmed that the status and protection of human dignity reflects a central issue in human rights. Conditions that enhance dignity of the dying experience are often reciprocally linked with autonomy expressed through sentiments of personal choice and control, using rights as the common basis for this association.

In response to the prompt "does dignity depend on how other people act towards you?" the general consensus approved the concept of bestowed or socially acquired dignity through vigorous head-nodding and murmurs of agreement. This relational aspect of dignity, noted to be consistent across all three groups, centred upon being treated by others with dignity and receiving high quality personal care. One person explained "Dignity for me is also about when you're not able to care for yourself and someone else cares for you and shows respect for you in that situation when you can't really express your needs" (Female, aged 36). Another person commented "it includes also respectful care, caring" (Female, aged 63). All participants were aware that at the end of life they may become dependent upon others and they prioritised receiving care that enhanced their sense of dignity. Dignity and respect are central tenets of care of the dying and earlier analysis of government healthcare policy in section 5.4 revealed these concepts to be grounded in rights discourses emphasising the need for good quality care and efforts that strive to maintain dignity at the end of life. Notably, no-one referred to the experience of witnessing a sudden, violent death, or considered the likelihood of this in their own end of life scenarios during any of the discussions. Instead, participant comments assumed that death would occur slowly as a result of chronic or degenerative illness and would, most likely, involve a period of incapacity. This is reflective of the late modern dying trajectory and it was interesting to observe how this awareness had filtered through to members of the public to become the socially accepted norm.

Speaking about the experience of her elderly father who had recently died in a care home, one participant illustrated her understanding of the reciprocal relationship between inherent and social dignity,

...it seemed that he had such lovely care because he was in a kind of care home, part of the NHS, and there was something about how carefully they treated him. The nurses there were just so nice and they also thought what a lovely man he was. He had dignity because he had a dignity within him (Female, aged 61).

Treating others with respect and care involves elements of bestowed dignity. In the above comment, this was interpreted as reflecting the inherent humanity and dignity within a person and this could be meaningful to those who knew the dying individual.

Dignity was discussed at length and in-depth which suggested that it was especially important to members of the public contemplating end of life. The findings of this thesis strongly suggest

that dignity is a central component of rights and, although the data from this stage of the research found that rights were not articulated *explicitly*, focus group participants did reference concepts associated with rights *implicitly* throughout their exchanges. Participants were willing and able to discuss, and elaborate upon, dignity in particular and this informed their perceptions of dying well. Even those participants who had some difficulty describing how they understood the concept of dignity were able to contribute to the discussion through their interpretation of what it meant to lose dignity. Not being able to describe what dignity *is*, but what it *is not*, confirmed that for these selected participants, it remained important. By way of illustration, an awareness of implied dignity that also included relational aspects of independence and control was suggested, “When you can’t look after yourself, can’t physically do things that you normally do, like going to the toilet, getting up and washing, dressing, and not being able to communicate” (Male, aged 65).

Control, personal choice, and the maintenance of independence in activities of daily living, especially personal hygiene, were considered important components of dignity. The third focus group in particular, spoke at length about the issue of personal hygiene and toileting as reflecting their interpretation of a dignified or undignified situation until the following comment referred to the case of Stephen Hawking and argued that “he managed to preserve dignity and value in spite of having almost no physical ability at all. It does make me think that perhaps even more important than the physical bit is the mental part” (Male, aged 75). This observation considered dignity and value as reflecting one’s own perception of self and state of mind rather than the outward physical, social or practical aspects. It was also the only comment made by a male who considered dignity as an inherent quality rather than a social quality. This prompts the question of whether men and women assess dignity by different standards. Do men identify dignity as primarily measurable in a physical or relational capacity?

During the course of long term illness, interpretations of what is dignified or acceptable may change. Perceptions of dignity are dependent on many factors and circumstances specific to the individual and the context. One person explained

I think the problem with dignity is that it’s subjective, highly subjective. What one person thinks is undignified for someone else, it’s been that way for their whole life. They’ve never had the liberty that this other person has. So you can’t talk about dignity as any kind of static benchmark (Female, aged 50).

This remark generated in-depth discussion on the concept of dignity linked to quality of life. Participants acknowledged that measures of life quality could change when diagnosed with

serious illness and challenge personal interpretations of human dignity. One testimony from a wheelchair dependent participant with a serious, progressive illness described

I knew how my illness was going to go. I knew that it would be gradually debilitating and I had goalposts. Used to think that when I reach this level I don't want to live anymore, and when I got to that level I thought "it's not so bad, I can still do this or that, I'll wait until the next level". And yet again, I say that the next level is the last level, yet again, and still now at the end level...the next level is the last level, but I'm here, I've got this far (Female, aged 64).

Human beings are resilient and their perception of dignity can shift over time. This was a new finding which had not yet arisen in the data; to suggest that dignity is not a static concept, rather it is subject to re-interpretation and re-evaluation, and this is key at the end of life where personal circumstances and symptoms experienced in the dying process can fluctuate over time. One male, (aged 60) in the same group spoke about a friend with Aids who had described his illness in a similar manner,

...if it progressed to a certain stage he was going to top himself. He wouldn't allow himself to live if this happened and he went beyond that. Then he got to that stage and it was alright and he said if he ever got to this level then just do me in, I don't want to live like that. But then he went through that again, as you were saying, the decisions you make will change. The human condition is infinitely adaptable and we will adapt to our conditions, and what we want to project for ourselves will change.

In the discussion on dignity, both these experiences invoked rational agency as a basis for individual liberty to determine and redefine their own boundaries and interpretation of human dignity as it changed over time.

Most focus group participants comfortably articulated what dying with dignity involved for them. This suggested that they had already contemplated their own death, perhaps through their involvement with Death Café discussions or their experiences of seeing loved ones die. Examples of dignified death were considered as "being allowed to go in your own time" (Male, aged 65) and "to have that sense that you've done what you can, that you've enjoyed what you can and that you are going with a sense of completion" (Female aged 67). These two comments made in lieu of each other by participants in the second group, understood a dignified death to comprise a sense of personal achievement linked to aspirations of autonomy suggesting dignity involved self-determination of the manner and timing of ones' own death.⁶⁷ Studies reviewed in section 2.2 proposed that maintaining dignity in conjunction with the feeling that life has been lived to the full, is constituent of a good death according to Western

⁶⁷ Personal experiences and backgrounds of group participants varied but their understandings and use of rights discourses involving liberty and dignity across all three groups was broadly consistent.

standards and this could support an argument for legalising assisted death in order to respect individual decision-making when one feels life no longer has a purpose or meaning.

The realisation of dignity in practice, was challenged by one group member who referred to the current legal status, “you can live your life with dignity, that’s up to you. But when it comes to ending your life, you don’t have a choice and that’s it, there is no choice at the end of life” (Female, aged 64). This participant referred to the legal prohibition of assisted suicide and limitations in regard to end of life decision-making to suggest that, while individuals are afforded liberty and can act with agency to maintain dignity in regard to their actions and preferences in life, a dignified death is not necessarily within your own control. Others supported the idea that death is often outside their control and unlikely to be dignified. There is provision in UK law and policy for individual choice in relation to some aspects of end of life decision-making that could enhance human dignity. However, the only legal option for an autonomous, dignified death that participants were aware of was self-starvation as discussed below.

Despite the debated nature of dignity in the literature, dignity was prioritised by most focus group participants across all the groups as an important concept. Reasons for this are not definitive. The Death Café concept does not particularly promote dignity, (or other values) but individual motivation for attending Death Café events could have been triggered by a bereavement or experience of serious illness provoking deeper contemplation of options at the end of life. Receiving medical treatment and attention in a hospital, hospice, or home setting will also have impacted upon individual perceptions of dignity. As one participant observed, dignity “also includes respectful care, caring” and personal experiences may have generated some thought as to the level of care and the manner in which care was given to themselves or loved ones. Dignity and dignity-conserving practices feature prominently as an aspirational standard in UK healthcare policy. This language may have filtered into the public discussion on end of life and been adopted on the basis that it is an accessible and generally agreeable discourse. In the 2003 House of Lords debates, Lord Laing highlighted the universal nature of dignity when he spoke of dying with dignity asking “Which of us...would not prefer to be given the choice to say enough is enough?” (House of Lords, 2003 col 1638). Many of the focus group comments also aligned dignity with choice. Their positions reflected an understanding of rights that strengthened a notion of human agency and may be empowering at the end of life. This way of understanding rights implicitly was evidenced in healthcare policy, the House of Lords debates and the campaign strategies of Dignity in Dying, but was embraced to an even greater extent through Death Café participants’ discussions.

8.1.2 Suffering

The concept of suffering was criticised in the literature as relative and having ambiguous meaning. Personal stories on the Dignity in Dying website addressed the issue of suffering in detail and reinforced this subjective and individual nature of suffering in an end of life context. However, analysis of their narratives identified three distinct components typifying suffering at the end of life: emotional anguish; physical symptoms; incapacity and decline. In contrast to these personal narratives, focus group participants spoke more in general terms and only for a short time specifically on the nature of suffering but their responses did depict an awareness of both mental and physical aspects of suffering. Most importantly, their comments disclosed that they understood suffering as a rational basis for having a right to die. Some contributions focused on physical symptoms, primarily pain

When people talk about it being acceptable for somebody to die, I don't think it's about any esoteric meaning of suffering. I think it's about being in pain and you don't want them to be in pain because that's miserable for them and you don't want people to be in misery (Male, aged 75).

I've been caring for somebody with terminal cancer who was in a lot of pain. This thing about "oh yeah we can control the pain", that's bullshit you know. They can keep increasing the morphine but it never seems to quite catch up... (Female, aged 50).

Other contributions discussed the differences and commonalities between physical and mental suffering

This goes back to the whole question of... whether mental suffering is not thought to be as bad as physical suffering... For me, I think physical pain is generally more bearable than emotional pain because emotional pain can go on for much longer and is more tortuous" (Female, aged 50).

...physical pain is also more socially acceptable and there is more room to say my back hurts because I fell over or a lorry got me, or I'm in excruciating pain, or how are you this morning? Oh, my back's killing me. But if people ask how are you doing this morning, and you say pretty bad, I see no hope in the future and I want to die..." (Female, aged 59).

Suffering as physical pain *is* more easily spoken about. Physical pain is often more visible and can be measured or related to concrete actions and experiences that form a generally understood basis for mutual sympathy and empathy. Findings of the group discussions gave the impression that physical pain and symptoms were involved in suffering and the desire to relieve that pain or distress was based on a natural instinct to enhance the well-being of

others. Interestingly, the vocabulary used to discuss this did not include compassion or sympathetic expressions grounded in compassionate discourses.

Emotional anguish, as part of death and dying, is more difficult to articulate in linguistic and relational terms. Our emotions, alongside our fears, are more private rather than publicly expressed. Even though focus group participants were aware of the spiritual and emotional components of suffering, they had difficulty describing this anguish and may, in this respect, be representative of the UK public in that they demonstrated unfamiliarity with articulating emotional pain and suffering. The language available to express emotional anguish may also be dependent upon social and cultural factors. Focus group participants were from a variety of different backgrounds. However, this finding contrasts to the rich and graphic descriptions of emotional anguish analysed in the personal narratives offered on the Dignity in Dying website. Without having access to detailed demographics of focus group participants including cultural and ethnic backgrounds, the reasons for this cannot be elaborated upon.

One group in particular linked the incapacity and declining health aspects of suffering with life quality. However, this, like suffering, is an ambiguous concept. What one person considers as suffering and an unacceptable quality of life, will be different from another as this example revealed

...seeing people who have had accidents and are confined to wheelchairs and can only move their head and they can operate equipment with straws, is that quality of life? Who would want to live like that? I personally wouldn't, but you can't say they have a crap quality of life because they might not (Male, aged 65).

Quality of life is a subjective concept that varies according to personal circumstances. In the same manner that perceptions of dignity can change, the understanding of life quality may need to be reinterpreted depending on variation in the progression and severity of illness or disability. One person related her understanding of life quality to dignity and noted in severe illness

...it's not just about dignity and dying, it's about dignity in life, living life and what counts in life and death, especially in intensive care units there is a blurring of the boundaries about what is life and what is death and I think doctors are in the dark about that. They make many hard decisions about what to do... (Female, aged 36).

The data from all stages of this research has demonstrated that the experience and articulation of human suffering in the dying process has increasingly been drawn into the end

of life debate through an association with, and understanding of, dignity and indignity. This is an unexpected finding revealing how the concept of human suffering has shifted from being traditionally located in faith-based or compassionate discourses, to rights discourses. Arguments by focus group participants and personal narratives cited in the DiD website in favour of assisted death, frequently raised the desire to alleviate unbearable suffering as a rational explanation for requests for assistance to die. In this way, they could achieve, what for them, would be considered a dignified death reflecting personal choice and control in the dying process. The experiences of focus group participants, in common with the personal narratives, supported a universal notion of frailty and vulnerability proposed by Turner (1993). In the process of dying, they suggested unbearable or protracted suffering and increasing levels of pain could disrupt self-embodiment and challenge individual values and human agency. Suffering was also perceived to be lessened through the maintenance of human dignity and, in this way, the experience of suffering has shifted from one that previously provoked a compassionate response to one that has become the domain of human rights, involving the preservation of dignity and the avoidance of indignity in dying. These findings suggest that in contemporary society, the desire to relieve suffering is based on recognition of the dignity of fellow man. Demonstrating a link between suffering and dignity underpinned by normative understandings of rights, could help explain how it is possible to extend the scope of rights so they can be used to validate and protect new interests or new claims not traditionally or usually defined in terms of rights.

8.1.3 Individual liberty

Despite a general reluctance to engage with human rights *per se*, most participants across each of the three groups prioritised the values of individual liberty and free will at the end of life. Strong personal convictions defended the notion of individual choice in end of life decision-making as a fundamental and innate value and this conception of liberty reflected a foundational position on rights. The underlying assumption for many of the participants discussing choice, was that human beings are rational, freely thinking and selective individuals. In the same way that they decide how to live their lives, control of their own death should also be free from interference by others. The following contributions were typical of those who emphatically defended freedom of choice underpinned by respect for human agency

I think we should be able to choose. It's us that's choosing. If you've got to the point where your quality of life is not as you've had it then you want to go (Male, aged 65).

...you are the only person who should be allowed to decide. Everyone should be able to decide for themselves (Male, aged 60)⁶⁸.

The majority of participants who firmly defended a notion of liberty regarded this freedom to choose and freedom to decide for oneself as an individual and universal value. All persons were considered sovereign over their own life and death decisions. (The few comments that rejected this application were defended from a religious or cultural background, as discussed below in section 8.2).

The curtailment of liberty in respect to end of life decision-making was strongly rejected by the majority of focus group participants, most vehemently by the same 60 year old male participant who continued

The thing that makes me angry is the disrespect for people who want to die. You are not allowed to say "I've had enough of this". That's what makes me angry, it's the lack of respect that no one individual has the right to say "I want out" and I think that's wrong (Male, aged 60).

This emotive outburst demonstrated a depth of feeling on the extent of personal freedoms. A number of participants prioritised unrestricted liberty and this included in circumstances where decisions taken were not necessarily in their best interests. Even where individual choices were not conducive to preserving life, there was an indication that an implied right to choose was important. In conjunction with this, the notion of mental capacity with regard to personal decision-making was discussed in detail and these findings are analysed in the following section.

Not all comments were so forcefully expressed. The desire for individual liberty in the dying process also surfaced in accounts of an ideal death as in this comprehensive example

I would like to have the option of assisted dying if I wanted to, and I would like to have the option of really good palliative care. I would like the option of having a death midwife with me and I would like to have my family with me. My ideal death is that I live a really long life in full vigour and social engagement and then I have a short illness that lasts maybe two or three months, so that I will be a little bit pounded and a little bit suffering. I think that's rather good because it makes you feel "done" that you've "had enough" (Female, aged 63).

⁶⁸ All male participants emphatically defended a conception of personal liberty. The numbers in this study are too small to generalise but further study to assess male/ female differences in attitudes to end of life could enhance an understanding of gendered perceptions on death and dying, including assisted death.

This scenario involved a number of options that may be available at the end of life and presented a stark contrast with the previous comment. Priorities in dying were expressed in terms of attractive possibilities and potential ideals rather than fundamental rights or entitlements that could be demanded. These two participants' attitudes at the end of life were clearly influenced by their individual backgrounds. The former participant's personal experience, which he openly shared, had shaped his views. He had had a serious accident that was followed by numerous resuscitation attempts and this had left him angry and feeling dissatisfied with the medical treatment he received, primarily because he had preferred to die at this time. The latter participant was a psychotherapist and bereavement counsellor whose husband had been killed suddenly in a road traffic accident with no opportunity to take leave of his family, put his affairs in order or make decisions about how he died. These very different experiences demonstrate how individual perceptions and thoughts on end of life may arise.

Only one participant observed that the exercise of individual rights could also entail a responsibility to consider the wider implications of human actions in relation to a community environment. This included an obligation to reflect upon personal choices with respect for other members of society,

...you are part of a wider social group. That idea of individual choice disconcerts me a bit because it suggests that individuals are on their own... But individuals are in a society and that determines what you desire in many ways, what you consider as your right (Female, aged 36).

This argument provoked a short reflection on the fulfilment of individual wishes against concern for the wider community. Participants acknowledged the sociable nature of human beings and a general desire to consider others. However, discussion then quickly turned to speaking about suicide and depression. These findings contrast with analysis of the data from the House of Lords where a large part of their debates was concerned with balancing the rights of individuals who request assistance to die with the rights of other members of society and discussion of state responsibility to protect potentially vulnerable groups of people. Reasons for this may be on account of their professional backgrounds. Many Members of the Lords were, or had been, connected with legal professions or institutions, and a number of focus group participants were therapists or counsellors.

Two out of three groups spoke in depth about self-chosen options that were available and permitted outside the traditional medicalised model of care. In particular, a natural death through the choice of self-starvation was discussed. One female (aged 67) noted

The medical profession has this duty to prolong life, but I think that if you have a choice, there are ways of saying that I don't want to die but I don't want to live anymore, so the way to do that is to stop eating and drinking and you won't last very long.

Apart from suicide, the only legal options for adults wishing to end their lives are self-starvation and refusal of life-prolonging medical treatment. To refuse medical treatment including artificial hydration and nutrition, adults must be deemed mentally competent (Mental Capacity Act, 2005). Participants shared examples where their loved ones had been recipients of a medicalised model of care or housed in institutions and had expressed a desire to hasten death through the refusal of food. These decisions were respected as a conscious demonstration of human agency as the following stories revealed

When both my parents died, they said they'd had enough and stopped eating and within days they were dead (Male, aged 65).

...she had been saying for years since my father died, 10 or more years before, that she wanted to die, but somehow not in a way that we quite believed...but right at the end of her life she said this in a new way and it was partly the exhaustion with the treatment she was receiving for all the infections and reacting badly to the antibiotics she was given getting nauseous...eventually we felt she said "enough of this" and she stopped eating and she died a dignified death, it was under her control, it wasn't painful, it was in a good loving place (Male, aged 75).

In each case, the experience of parent death was perceived as natural and dignified, occurring as a conscious response to illness and one that was determined by themselves. The option of self-starvation reflected autonomous decision-making at the end of life in a difficult situation where there was an opportunity to control the timing of death and achieve this in a dignified manner. Appetite is suppressed as a side-effect of many illnesses. The body does not need the same amount of nutrition when inactive, and self-starvation, although it may be prolonged and sometimes uncomfortable, does reflect human agency and facilitate a natural death.

Although it was not expressed explicitly in the language of human rights, personal choice involving human agency was respected. This was articulated at times as *control* over the dying process, and from a participant perspective, as revealed in the following contribution, this also had implications for human dignity,

...control is very much a part of it, in the sense of control of what happens... When I say control, what I mean is, having some agency which need not involve being able to wipe your own bottom but it must involve being able to connect with other people (Female, aged 75).

Participants across all focus groups agreed that choice at the end of life was important. But, as with the concept of suffering, they spoke in general terms rather than specific wishes or plans.

In one group this led to wider discussion about the extent and relevance of choice, including the ability to make choices prompted by this comment

I think choice should be there in healthcare much more, but the problem is, how can you decide what you want if you don't know what it's going to be like? When you're judging your death from the vantage point of life and you don't know how you're going to die? (Female, aged 36).

Despite advances in medicine and technology, the symptoms and prognosis of the individual dying trajectory cannot be accurately predicted and whilst one can plan, prepare and state personal preferences, the availability and ability to fulfil these cannot be guaranteed. There is information available with regard to existing legal provision for choice at the end of life. Advance Directives and Lasting Power of Attorney were briefly mentioned in the focus groups, but only one person had written an Advance Directive and there was a general lack of knowledge concerning these. Where discussed, participants thought these could be a useful indication of personal wishes but were unsure of their legal validity or how they would operate in practice.

8.1.4 Capacity

In connection with discussions about individual choice, the concept of mental competence arose and this was addressed in-depth in the first focus group. Respect for fundamental human liberty is supported by a natural law perspective on rights, but there is a historic and philosophical importance attached to *rational* decision-making within this approach to rights. Mental competence as defined in the Mental Capacity Act 2005 has featured as a safeguarding criteria in all of the House of Lords Bills examined in Chapter 6, to ensure that only requests from rational individuals with certified mental capacity are permitted assistance to die. This criteria of mental competence, whilst argued as a necessary safeguard, negates an idea of universal and innate human rights to suggest that rights are only held by rational agents.

In a contemporary UK context, rational capacity is determined by psychiatric assessment. Some focus group participants argued that mental competence was an important consideration in regard to end of life decision-making, particularly among the frail or elderly who could be influenced by others,

As you get older, thinking about my mother, I don't think she was as capable mentally at the end, so she wouldn't have been thinking with as good a mind as to when she was younger so I think that when people are old they can be swayed, so there is the

worry of undue influence that people could influence them to make a decision (Female, aged 58).

The degree of what is classified by the lay person as acceptable mental capacity is often difficult to define and capacity is inclined to fluctuate depending on the nature of illness, life events, and possible side effects from medication. This participant who referred to her own mother, associated being “capable mentally” with being of sound mind and not being susceptible or prone to influence.

The notion of undue pressure is cited in opposition to the legalisation of assisted death and is relevant to the end of life debate, but was not considered or indeed prioritised by all focus groups. One participant dismissed the influence of undue pressure solely in older age

Throughout your life everybody influences other people to make decisions that they wouldn't if so and so hadn't said such and such so it's not anything different to normal is it? The idea that only when you're old can you get pressured into making decisions that you're not happy with...it's just not real (Male, aged 60).

Although not typically part of a rights discourse, these concerns regarding capacity and undue influence are indirectly associated with understandings of rights because they are grounded in the limitation of personal freedoms, which has implications for human agency.

In cases of chronic, debilitating illness, it would not be uncommon to experience periodic feelings of hopelessness, depression, and psychological stress. Clinical studies in Chapter 2 revealed that incidences of depression were often used to question decision-making capacity and mental competence at the end of life. Focus groups did discuss severe depression in relation to requested death but participant contributions were most commonly related to their experiences of suicide. Rights discourses were not explicitly evident, but rather implied, through their contributions that inferred the decision to end one's life was an expression of individual liberty. The following comments were indicative of this sentiment

Those suicides where there isn't an irrational 'relieve me of my anger element' are well thought out and even discussed and planned and things are put into place (Female, aged 63).

I had a friend who did kill herself...I felt it was a waste but I knew how much she suffered and I respected that decision. She did it in a very clever way, she'd researched it, been on assisted dying sites on the internet, she'd set things up to do it properly (Female, aged 50).

I don't think you can say everybody who commits suicide is depressed. Some people think 'you know what, it isn't for me' and they make a long plan and afterwards families will discover that everything has been put neatly in order (Female, aged 67).

Participants related their thoughts to incidences where depression was linked to suicide and wanting to end their own life, but their own experiences (of family and friends' suicides) testified that suicides were not solely associated with depression. There were other factors involved and suicide could, and on occasion, should, be considered as a rational option. These experiences described suicides that were contemplated, planned or shared in advance. General impressions of suicide not indicative of a "relieve me of my anger element" were mostly regarded as a rational decision demonstrating regard for others and reflecting individual choice.

Accounts of rational suicide challenge the historical and medical assumptions that has traditionally stigmatised suicide as a desperate and violent act, and literature positioning suicide with insanity and depravity. Focus groups instead articulated a sympathetic understanding of individuals who took steps to end their own lives. Not negating the need for stringent monitoring in general, and *some* level of competence in end of life decision-making, if the person has a settled intent to end their life, one must also respect decisional autonomy as an innate human value. At what point is individual mental capacity deemed not worthy of determining the end of life? Analysis of focus group discussions highlighted that dying is individual. There are deaths that include incidences of depression, and behaviour often outside what may be considered in healthcare as competent, but respect for personal liberty and human agency in the dying process was commonly and consistently prioritised.

8.2 Alternative perspectives on death and dying

In general, focus group participants inferred and understood concepts of individual liberty, freedom of choice and the maintenance of human dignity as the basis for having a right to die. This supported the literature that observed a decreasing trend in religiosity and rise in secular attitudes. However, a minority of individuals expressed their opinions on end of life from alternative perspectives. An understanding of rights used to determine the dying process was negated or challenged by some participants on account of their cultural backgrounds and religious beliefs. One participant defended her general reluctance to consider end of life choices and referred to her religious background that attributed decisions about the timing of death to a divine source rather than one determined by man. She explained

...this comes from a longer belief that I have that when my time is right, I will know and have chosen it on another level. Therefore there is no need for me to be obsessed with death, more like how I live my life and when I start running out of time because I am

getting older to say, 'what choice is there today to live?'...a dignified life with my fellow beings and myself (Female, aged 66).

For this person, her religious belief also determined her attitude and understanding of a good death, "I would allow the illness or whatever is going to take me, to take me naturally" (Female, aged 66).

Group demographics in relation to religious beliefs were not recorded in the data. Initially there appeared to be a high incidence of secular perspectives suggested through enthusiastic support for individual liberty and self-determination in all aspects of life and death. However, during the course of discussions, religious convictions became apparent and were shared openly by some. A number of participants expressed their commitments and values as "spiritual". References were also made to the Christian, Catholic and Jewish faiths. One person who discussed her spiritual beliefs criticised the increasingly secular and physical parameters employed by contemporary society to address dying. She argued

We don't consider our spiritual being and we are in a box labelled "I am a suffering body, or a suffering mind" ...we make decisions based on our pain and suffering rather than the greater things that there are that we can't access when we are in pain and suffering and also on medication (Female, aged 60+).

This participant had a firm belief in the after-life reflected in her interpretation of a good death and wishes at the end of life,

For me it would be to have somebody there with me to remind me that I'm going to a better place and not focus on all the things that are wrong with me, the hospital, the tubes, and the needles and all that, but that the soul is going to a better place and will return in a better way (Female, aged 60+).

Religious belief, including belief in an after-life, may negate the importance of rights in relation to end of life. A few participant contributions appeared dismissive of rights discourses in preference to faith-based discourses. For these individuals, the experience of dying was not the ultimate end. Instead, individuals were being rewarded by "going to a better place". Ethnicity was not recorded as part of the information requested from participants but throughout the discussion those, other than British descent, identified themselves as Canadian (2), Greek (1) and Brazilian (1). The Greek and Brazilian participants, in particular, expressed difficulty in thinking about choosing the manner or timing of their own death. This, in part, could be associated with their respective orthodox and spiritual faiths which were discussed, plus their cultural backgrounds.

Two participants spoke of their experiences in caring for a dying parent and these contributions did support the perhaps easily disregarded notion that dying could be a period of transformation and growth both for the dying individual and care givers. These findings complemented the religious argument that dominated the 1936 House of Lords debate and has also arisen in subsequent debates; life is sacred and can be valuable even in the dying period where suffering is present. A 66 year old female participant explained

My mother had four months before she died and we had to clean her bottom and for her it was awful, and yet what she learned and what my sister and I learned, was amazing ...To see her having to trust us and to let go of her power and her capacity into our hands was a huge thing for her, but it was quite amazing how she transformed herself in those four months.

A longer living/ dying interval arising from chronic illness is dominating the late modern dying trajectory and this has implications for human agency and personal liberty as the dying person becomes more dependent on others and must relinquish some aspects of liberty, in some cases including the ability to independently manage personal care. Participants considered the loss of freedom to manage personal hygiene and self-toileting to have an impact on dignity at the end of life. This finding contrasted with the clinical studies conducted by Gennip et al (2013a) that suggested physical symptoms were not significantly related to dignity. This confirms the subjective and relational nature of human dignity. The above account, despite having to perform intimate, personal care demonstrated how the dying process could involve a period of reconciliation with family members and enable personal growth.

At the end of life, all human beings become vulnerable, and participant accounts of the dying experience of loved ones did support a universal notion of frailty and vulnerability. Human vulnerability in the dying process also influences the nature and quality of personal relationships with others as was observed in this account of caring for an elderly parent,

...your vulnerability is no longer something you can hide, and that gives you such a chance for growth in the dying process...she allowed me to be close to her and we shared...she had been so emotionally closed and she became so open (Female, aged 63).

Focus group participants admitted that vulnerability in the face of death, combined with great suffering, could challenge established beliefs. Speaking about the experience of a religious friend who pleaded for assistance to die, one person shared

I know that even goes against his own belief. He would generally have thought that suicide was wrong, he was a Christian, a pacifist, a conscientious objector, he thought killing was basically wrong and yet he was begging me to kill him because he had basically had enough of the pain (Female, aged 50).

As increasing levels of pain disrupt self-embodiment and challenge one's values and beliefs, actual or anticipated suffering is increasingly used to justify the arguments for an assisted death. Even prominent religious figures, as illustrated through the example of former Archbishop Lord Carey in section 6.3.1, have been persuaded to change their position and support an assisted death for some individuals, on account of their having witnessed unbearable and protracted suffering.

One participant challenged requests for assistance to die disputing the desire to die as valid or rational. Their opposition had a background in the Jewish faith which prohibits suicide as an immoral act. She argued that great suffering *could prompt* claims for a right to die, but felt that this still did not validate a request to die,

No-one wants to die, what they want is an end to the conditions that they are experiencing in that moment that is causing them to suffer physically or emotionally, and were you to wave a magic wand and take away that suffering as often happens with people who do get better and don't die when the doctors tell them they will...they are glad they didn't...we need to differentiate between people wanting to die which is the experience and to make that distinction that they don't really want to die, they want to have the conditions different (Female, aged 59).

Initially this resonated as a well-articulated and valid point. If the conditions causing suffering were to be removed, then the individual would no longer be experiencing suffering and therefore not want to die. This comment also demonstrated awareness of a clear distinction between wanting unbearable suffering to end through death, or the preferable option of ending suffering that was separate from wanting to die. However, this viewpoint was quickly contested. Arguments were made that some individuals do, for different reasons that may or may not include suffering, wish to die, and that this show of self-determination was equally worthy of respect.

Conclusion

The data in this chapter appeared initially to contrast with the earlier research findings that revealed human rights discourses to be central to the UK end of life debate and policy on assisted death. The responses presented by focus group participants seemed inconsistent with other findings to the extent that rights seemed superfluous to public understandings of death and dying. When asked directly, participants had difficulty articulating or even attempting to articulate how they understood a right to something and what having a right to something could/ should/ would entail. This was surprising, but perhaps my own knowledge of conceptual

understandings and discursive expressions of rights should not have led to an assumption that group participants would be using this language. Selected members of the public, through their personal contributions demonstrated that they were not familiar or comfortable with *explicitly* using *rights* and had a very limited understanding of human rights *per se*.

Analysis of focus group discussions revealed that *explicit* references to rights, including a right to life or a right to die were not articulated and a “right to choose” was expressed on only one occasion. However, if participants did not directly adopt rights discourses in contemplating death, they did nevertheless express their priorities at the end of life and desires for a good death grounded in an *implicit* understanding of rights. These *implied* associations, commensurate with the personal narratives analysed in section 7.4.2, primarily included individual choice and a desire to alleviate suffering in order to maintain human dignity. Concepts underpinned by a notion of human rights, including choice and control, were valued so that rights were implicitly understood to promote and support human self-determination and free will as a natural desire. By implicitly using components of rights discourses, the prioritisation of individual liberty was foregrounded in focus group discussions through definitive support for human agency and confidence in the ability of individuals to evaluate and determine their own values and beliefs in relation to life quality and end of life choices. Choice was frequently highlighted as important by participants who respected this as an expression of free will and rational self-determination perceived as inherent in human beings.

The majority of contributions, in all group discussions, demonstrated compelling support for individual freedom with an emphasis on choice and (mostly) rational free will, suggesting these as the basis for making claims at the end of life. That said, participants also acknowledged the uncertain and ambiguous extent of choice. At the end of life, prognosis and symptoms are often fluctuating and difficult to predict which makes decisional autonomy difficult, but participant sentiments expressed that the experience of suffering and perceptions of life quality could only be determined by the dying individual. On this basis, the ability for autonomous decision-making should be maintained. In general, participants felt that they were entitled, or ought to be entitled, to make their own decisions about the manner and timing of their death. Some emphasised this as a fundamental aspect of being human, others seemed more ambivalent and considered the ability to choose as desirable, but not essential.

Respect for autonomy in dying can be grounded in universal notions of human frailty and vulnerability including losing independence, self-identity and altered relationships with others and the community. Analysis of the data in this chapter builds upon findings from the preceding data to suggest that it was not the physical act of *being* in control, but rather the emotional *feeling* of being in control that is important in the dying process. This *feeling* of being in control was linked with notions of agency, identity and human dignity that emphasised the importance of dignity in dying. Perceptions of focus group participants that are to some extent representative of the public was that the maintenance of human dignity was essential, particularly at the end of life and in circumstances where independence may be lost and the opportunities for autonomous decision-making become less, or less highly, regarded.

Participant engagement with the concept of human dignity suggested that it was prioritised highly at the end of life. All participants could speak at length on their interpretations of human dignity in relation to dying well and for many this involved aspects of autonomy and human agency. Dignity as a concept was discussed in depth by participants. Their understandings supported and elaborated upon earlier suggestions of an inherent dignity indicative of a foundational position on rights expressed as “a dignity within him”. In this way, human beings were understood to be entitled to dignity solely by virtue of their humanity. Seeing loved ones treated with dignity was also interpreted as a reflection of one’s inner dignity “in a situation when you can’t express your own needs”. The exploration of dignity by participants is grounded, one could say, in a foundational perspective on dignity as a component of rights, but might also be understood from an anti-foundational or constructionist approach. The constructed nature of dignity was illustrated, by way of example, in the comment on dignity as a value being “more societal than personal”. Participants acknowledged the relational aspect of dignity as a social concept that could be accorded to a situation or bestowed upon an individual, or indeed lost or taken away by human action or circumstances.

In response to a direct question on rights, there was widespread agreement across all groups that individuals *did* have a right to request assistance to die, but there was a general lack of knowledge of the law and little mention of a legal framework of rights in relation to determining options at the end of life. Even when discussed in the context of law and having a legal right to die, the public discourse on dying eschewed respect for a legal approach to rights.

Participants did refer briefly to the necessity of law around the issue of assisted death to prevent indiscriminate “bumping everyone off”, and a necessary degree of professional regulation to ensure failed suicides did not “botch the job”. Participants were also aware that the current status of assisting a suicide was illegal. They spoke instead about other options at the end of life, including suicide or self-starvation, which, in their experiences of parent death, had been a relatively peaceful, natural, and dignified death reflecting a method of self-determination in the dying process.

Focus groups did, on a few occasions, mention contested areas in relation to legalisation of assisted death. These mirrored the issues raised in the House of Lords debates but were not expanded upon or discussed in depth. Therefore they were not addressed specifically in this chapter. These included: the role and nomination of duty bearers (in the words of one male participant, aged 65 “who is going to do it?”); the possibility of undue pressure; confusion over the safeguarding criteria, and definition of a terminal diagnosis (“well, what’s terminal then?” female aged 64). In general, participants did not regard a legal positivist approach to assisted death highly. This was evidenced by instances where individuals had assisted in a death or where they expressed the prioritisation of autonomy and choice to attain a dignified death over respect for the prohibited status of assisting a suicide.

The group discussions revealed a small number of contributions grounded in a religious or cultural background that were sceptical of a notion of rights and, in contrast to the majority of participants, did not prioritise individual liberty and freedom of choice as inherent and innate values. This position was similarly articulated in the House of Lords debates, most notably in 1936 in opposition to the legalisation of assisted dying. At the end of life, values and beliefs are relative. They are influenced by socio-cultural norms, personal experiences and the dictates of individuals, families, institutions, whole societies and discourses that changes over time.

Analysis of focus group discussions in common with the earlier research findings has corroborated that rights discourses are articulated by a range of social actors who apply *their* understanding and interpretation of rights in a range of contexts. Group discussions with Death Café participants contemplating end of life, has provided an original analysis of these voices in the debate and contributed to an explanation of *how* and *to what extent* particular discourses are adopted or rejected to ground individual values and beliefs. Group discussions

indicated the ways in which prevailing discourses were received by the public, and contributed to shaping their opinion. In the focus groups, it appeared that an *explicit* discourse of rights had not ensconced itself in participants' vocabulary. There was limited references to rights *per se*, and they seldom used the language of rights directly to share their perceptions of death and dying. However, they frequently used an *implicit* understanding of rights, underpinned by an essence of rights that primarily invoked respect for individual liberty involving choice and human dignity. Most contributions implicitly drew upon rights discourses to describe what dying well meant to them as individuals as they shared their personal experiences and debated differences of opinion. The overwhelming impression from focus group participants highlighted that at the end of life the opportunity to die well and experience a good death was universally desirable. The majority of participants, in common with other actors who supported the option of an assisted death, thought this to be enhanced through respect for individual liberty, beholding a sense of identity based on human dignity and maintaining the feeling of being in control to achieve the death that would reflect their personal values in life. In this way, the responses of focus group participants complemented the earlier research findings and helped confirm the notion that human rights discourses have become central to the current UK debate on end of life.

CHAPTER 9

Conclusion

Interest in this research area was triggered by my own perception that human rights discourses were becoming more prominent in defining end of life. The ways in which end of life issues, including the option of assisted death, are articulated and understood has implications for how individuals think about death and dying. Assisted death, expressed by a number of social actors as a "right to die", is a controversial and very personal topic but one that was important to address in light of the late modern dying trajectory, and, on the basis of

the universality of death. Premised on a social constructionist approach, this research has enabled comprehensive exploration of the discourses used in end of life policy and debate, to reveal how rights can be interpreted and applied in a different context. The findings of this study confirmed that human rights discourses have become central to end of life policy and debate in the UK. They have impacted our understanding of dying but in ways that are complex, and arise as a reflection of dying at a specific period in history.

The purpose of this concluding chapter is to draw together the different threads of my research and findings to explain, through analysis of the data, *how, when, for what purposes*, and to *what extent*, rights discourses have become central to death and dying. It will also illuminate the role of different social actors who have articulated and understood rights discourses in this context. This chapter is divided into six sections to reflect the research findings. The first section reviews the contemporary landscape of death and dying to contextualise a notion of rights at the end of life. The second section explores how different approaches to rights inform the understandings of rights that social actors draw upon. Across all stages of the research there were both similarities and differences in the use and interpretation of rights discourses. Prior to discussion of the data, the main findings are presented in *Figure 9.1* for the purposes of clarification and illustration. This table summarises: how; when; for what purposes, and to what extent, rights discourses have featured in the research. The third part of this chapter demonstrates, through document analysis, how rights are currently being defined in UK law and policy, although this has been challenged in a number of ways. The fourth section examines how explicit and implicit understandings of human rights have been used to argue both for and against the legalisation of assisted death during the historic and contemporary debates. The fifth part of this chapter refers to the case study analysis of Dignity in Dying to illustrate how a rights-framed approach was used by a campaigning organisation in an end of life context. The findings from focus group discussions with Death Café participants are discussed in the sixth section to reveal how they understood rights with regard to death and dying.

9.1 Contextualising rights at the end of life

This study has confirmed that there is, at present, a high level of public engagement with the end of life debate. Issues associated with death and dying are increasingly being brought into the open in a number of different ways. Political debates have taken place in both the House of Lords and the House of Commons, high profile figures have publicly spoken out about their

views, and emotive legal petitions have been raised by individuals requesting an assisted death, all of which have received extensive media coverage. The activities of “right to die” organisations are encouraging public awareness and support for assisted dying through various strategies involving mediated communication, public demonstrations, lobbying, and locally targeted campaigns. Death is becoming more visible through a number of public, and private enterprises, independent initiatives, and social franchises such as Death Cafes, workshops, support groups, and festivals. The Dying Matters Coalition offer a wide range of resources to help people discuss death, dying and bereavement. Their reach extends across a host of different organisations and they promote local and national events to raise awareness of end of life concerns. These efforts have stimulated discussion in the public domain so that end of life concerns are now considered less of a taboo and more easily spoken about.

Changes to the late modern dying trajectory in Western societies have been facilitated by advances in medical technology enabling early diagnosis and the possibility of treating a host of potentially life-limiting conditions. This has resulted in a longer life expectancy and one that typically involves chronic, or serious illness, and multiple ailments. As follows, individuals now have an extended period of time to reflect on their situation and prognosis, and this raises new areas for debate. NHS management of health and illness, through a doctor-led medical model of care, is becoming indubitably contentious. The limits of currently available options at the end of life are heavily criticised by some and the patriarchal model of care with associated superimpositions of knowledge and power is being challenged by individuals who are increasingly demanding respect as a self-determining participant in the dying process. This has been exacerbated through an emerging emphasis on, and prioritisation of, individual choice that is reflected in the marketisation of healthcare provision and the positioning of patients as healthcare consumers.

In light of the decline in traditional religious and community frames of reference, discussed in section 2.2.2, individuals are more commonly negotiating and validating their own lifestyle choices. These choices, to some extent, are shaped by the prevailing discourses. The findings of the data confirm that human rights discourses involving concepts of individual liberty and human dignity have become central to the debate on end of life and this represents a shift in ways of thinking about death and dying in contemporary UK society. Individual liberty, expressed as choice and control has been prioritised and a strong correlation between a sense of dignity and autonomy has developed. These concepts were revealed through this research as key to influencing current attitudes towards the end of life. Some actors have interpreted this as suggesting that individuals could, or should, be permitted to decide the manner and

circumstances of their own death, and this includes requesting help from others to assist in their death.

Attitudes towards death and dying in late modernity have been transformed by the application of rights discourses, to the extent that assisted death on occasion is expressed as a *right to die*. The notion of rights is, as this research has discovered, currently being thought about in a new context. The process of dying is especially personal. An understanding of rights at the end of life is being applied to enhance the idea that individuals are sovereign over their own property and able to self-determine, *not only how they live, but how they die*. The effect that particular discourses have on social, political, and cultural processes has been a fascinating area for study. During the research process, it became evident that more clarity was needed to ascertain *how* rights discourses are employed and understood at the end of life and to focus on the actors who are using this. This research was able to offer some explanation for *how*, *when*, to *what extent*, and, for *what purposes*, issues at the end of life have come to be articulated using rights discourses, and on what basis assisted death may be conceived as a right to die.

9.2 Contemplating human rights

The findings of the data suggest that the ways in which a right to die could arise and operate in practice depends on how rights are understood, and imbued with meaning, by different social actors. Sociological research on death and dying had not explored how aspirations and values at the end of life have come to be articulated as “rights” or the role of actors that are using this discourse. Human rights frameworks were examined in Chapter 3 to explore different positions on rights that social actors may use, and to assess, on what basis, a right to an assisted death could possibly be envisaged. Both foundational and anti-foundational approaches to rights could arguably validate a right to determine one’s own death and both these approaches were evident in the research data as it emerged. Through a foundational position on rights, pre-social, innate values of liberty and dignity were grounded in a common humanity. Freedom to determine the manner and timing of one’s own death could be defended through this approach to rights that emphasised individual liberty, human dignity and, in light of Bryan Turner’s contemporary contribution to a foundational ontology, human frailty in the dying process. This position suggests a fundamental right to die on the basis of man as a rational, freely choosing individual, sovereign over matters of life and death. A foundational approach to rights also respects human dignity as inherent. A right to die could

similarly be conceived through the desire to maintain a sense of dignity in the face of suffering, or to avoid potential indignity at the end of life. Turner's frailty theory of human rights is underpinned by a notion of vulnerability of the body, and, by virtue of all individuals being vulnerable in the face of their own mortality, the idea of universal human rights at the end of life is enhanced. Given the certainty of death and uncertainty of the dying process, which leaves individuals vulnerable, a foundational perspective could reasonably be argued to support personal choice at the end of life and protect the dignity of the dying.

An anti-foundational approach to human rights offers an alternative basis upon which to consolidate the values of individual liberty and the preservation of human dignity at the end of life. Legal positivism is reflective of an anti-foundational approach to rights, which recognises rights as legal entitlements. In the UK, established legal instruments, including the HRA 1998 and ECHR 1950, currently protect individual liberty rights relevant to the end of life. These include: the right to life; the right to privacy; the right to freedom of expression; anti-discrimination rights, and protection from inhuman or degrading treatment, all of which are conducive to maintaining human dignity. With the exception of the right to life that is non-derogable, the other rights may only be curtailed in the interests of national security, public health or where fulfilment of these rights are detrimental to other members of society (HRA 1998, ECHR 1950). Analysis of the two most prominent cases of Diane Pretty and Tony Nicklinson revealed how these provisions have been interrogated and used to question the boundaries of specific legal rights. New configurations of rights that challenged the scope of existing rights referred to in these legal petitions included a right to die and a right to waive the existing right to life. Driven by these appeals and wider debates involving the interpretation of rights at the end of life, in particular the right to privacy, the issue of requested death has become so tangible that there is a possibility of the UK law courts making a Declaration of Incompatibility, or using the principles of statutory interpretation to override current provision. In this way, a right to assisted death could be established through setting a legal precedent.

A social constructionist approach is also part of an anti-foundational position that disputes rights as inherent and pre-social. In contrast to validating rights through *legal* entitlement, social constructionism enables a focus on the *social* life of rights, exploring how claims to rights arise in response to, or as a reflection of, a specific time and social context. In the section above, death and dying were contextualised within a contemporary, Western frame of reference to illustrate how different interpretations of rights were coming more into focus. The media, and "right to die" organisations, have been particularly persuasive in developing a

notion of *rights at the end of life*. The adoption of specific language strategies has been shown to function as a powerful tool that can shape the way that people think about, and give

RIGHTS DISCOURSES	Law/ policy	Legal cases	House of Lords debates	Dignity in Dying	Focus groups
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meaning to, their interests and this can also “sustain a system of beliefs” (Hastings, 1998:193). This research has explored Dignity in Dying in relation to their use of rights discourses as an organisation that campaigns to legalise assisted death and discussed how this may influence attitudes and values towards end of life. Through framing the notion of requested death as a *right* to die to reflect their ideals of choice, human dignity and relief of suffering, Dignity in Dying have constructed a new narrative of assisted dying. Framing human rights as *claims to* something, in this case a right to die, can be empowering and through foregrounding specific aspects in the debate the objectives of the organisation may appeal to a number of target audiences. The example of DiD has demonstrated how one campaigning organisation has used rights discourses strategically to construct and articulate the right to an assisted death through a common desire to experience a *dignified and good* death.

Exploring the use of rights discourses from a sociological perspective has helped illuminate the ways in which understandings of rights have been appropriated and embedded in the context of death and dying. The main findings from each stage of the research are presented below in table format, before being discussed further. These findings offer answers to the questions initially posed in the introductory chapter. By way of illustrating *how, when, for what purposes, and to what extent*, rights discourses have featured in the data, the findings contribute towards answering the question by Scolding (2011:320), “how can a right to something that inevitably happens to all of us suddenly arise”?

Figure 9.1 Illustrating how, when, for what purposes, and to what extent rights discourses feature in the data

How	Not expressed explicitly in Homicide Act 1957 or Suicide Act 1961 with regard to assisted suicide. Used explicitly and implicitly in policy, but variable and ambiguous“ eg “right to be treated with dignity and respect” (NHS Constitution, 2013)	To challenge scope and boundaries of existing human rights principles in ECHR 1950: Art 2 right to life; Art 3 prohibition of torture; Art 8 respect for private and family life; Art 9 freedom of thought, conscience and religion, and Art 14 prohibition of discrimination	Explicitly and implicitly to define arguments both for and against legalising assisted death. “Right to choose” at end of life aligned with other fundamental freedoms	Explicitly through “right to a dignified death”, “right to a good death” and “right when dying, to die well”. Implicitly, through personal stories, as choice and relief of suffering.	Not used explicitly, and had difficulty engaging with rights as such. Understood implicitly through liberty, dignity and vulnerability at end of life
When	Increasingly features in end of life policy. In 2015, “choice” as the dominant rhetoric (Borgstrom and Walter, 2015)	<i>Bland</i> 1994 initiated legal interest, but not explicitly citing rights. Appeals increasingly based on deliberating rights, especially <i>Nicklinson</i> 2012 case	Minimal in 1936 (twice mentioned). Increased over time. Most prevalent in 2014. Displaced historic, compassionate discourse	More prominent over time. Since 2006, added focus on “dignity”. Strategic use of rights maximised with regard to social context	Takes place in static, contemporary context therefore no historic comparison
For what purposes	To establish normative frameworks and standards of care. To define these using widely appealing and acceptable discourses	To legitimise individual liberty to determine end of life (with assistance). To achieve dignified death based on rational choice.	To oppose and support right to assisted death. To debate the nature and boundaries of individual liberty rights	To resonate with public and political figures, to foster collective identity, to mobilise public support, and, ultimately, achieve legal change	To achieve a good death. (No apparent political or organisational purpose).
To what extent	Central to policy. Emphasis on dignity and dignified care. In law, through HRA 1998 which protects principles of dignity and liberty	Maintenance of dignity prioritised in <i>Bland</i> , <i>Pretty</i> and <i>Nicklinson</i> . Grounded in Arts 2,3, 8, 14 (ECHR 1950)	Contemporary debates operate on terrain of rights, balancing individual rights with community rights and protection of the vulnerable/ fear of slippery slope	Central in 2014 campaign context. Liberty as fundamental and historic value, expressed as “choice” and “control”	Dignity as key value, commonly prioritised. Includes recognition of inherent/ social dignity and encompasses understanding of human agency and choice

9.3 Advancing human rights principles to challenge UK law and policy

This study explored the current provision for end of life in existing UK law and policy documents to find there were a number of ambiguities and areas open to challenge. The terms “assisted death” or “right to die” were not found in statutory law. “Assisting suicide” was defined in the Suicide Act 1961 where the act of aiding and abetting of suicide was, and still is,

punishable with up to 14 years imprisonment. An interesting discovery in this research was the *Policy for Prosecutors in Cases of Encouraging or Assisting Suicide 2010* document. This policy was formulated by the Director of Public Prosecutions in response to the legal appeal of Debbie Purdy in 2009. The policy was intended to reduce the legal ambiguities surrounding the circumstances under which prosecution was likely, or less likely, to occur in cases of assisting suicide by listing mitigating factors. Development of this policy indicated some recent interest, and possible opportunity for interpretation in the law with regard to assisted suicide, particularly where this was driven by compassion. It also highlighted the need to develop an appropriate legal response in cases such as these. This research unveiled a lack of prosecutions by the Crown Prosecution Service in cases where encouraging or assisting suicide was suspected, which did suggest that, in certain circumstances, assisting death is being tolerated through guarding the exercise of discretion.

Analysis of the law, rather surprisingly, revealed additional circumstances where unbearable or prolonged human suffering justified the ending of life without being subject to risk of criminal prosecution. Legal provision in the Criminal Justice Act 1967 permits doctors to end life through the doctrines of “double effect” that involves administering sometimes lethal doses of medication and “letting die” where life-saving treatment may be legally withdrawn or withheld. These findings demonstrate that, where great suffering with little or no possibility of recovery is evident, there is, again, some degree of scope for interpretation in the law. In these examples, the law supports the medicalised model of care. Decisions are made in, what is deemed by the medical profession to be, the patient’s best interest, and these actions are permitted and protected in UK law. The language differs, but the notion bears a similarity to the contributions of the 1936 House of Lords Voluntary Euthanasia (Legalisation) debate that also held a patriarchal model of care in high regard and considered unbearable suffering to justify the act of “mercy killing”, as it was framed at that time. The doctor-led model of healthcare is, in contemporary UK society, being increasingly challenged by an emphasis on patient participation and this is enhanced by human rights discourses demonstrated through this research as holding traction in an end of life context.

Healthcare policy, including the NHS Constitution 2013 and the End of Life Care Strategy 2008, prioritised respect for personal *choice* in end of life decision-making and the importance of *dignity* and dignified practices as standard. The concept of choice is the principal rhetoric in government policy, revealed in this research through Borgstrom and Walter’s (2015) comparative analysis of “choice” and “compassion”. Dignity is also emphasised. The conservation of dignity is prioritised in a similar manner to personal choice, which suggests

rights discourses have become central to defining end of life care. The importance of human dignity was reflected in the NHS Constitution 2013 that considered the “right to dignity includes a right not to be subjected to inhuman or degrading treatment”. This rather peculiar example not only constructed a *right to dignity* but proposed that it includes an already existing right not to be subject to inhuman or degrading treatment through perpetuating suffering at the end of life and impinging upon the agency of the dying individual. This amalgam of rights is grounded in ECHR 1950 Article 3 that was similarly used in the legal petition of Diane Pretty in 2001. *Pretty* claimed that in not permitting a right to assisted death, she was forced to suffer an undignified death by remaining in an intolerable situation which constituted inhuman or degrading treatment.

Analysis of healthcare policy discourses demonstrated a strong correlation between a sense of dignity and liberty to control life and death events. There *are* possibilities for autonomous decision-making at end of life. These presently exist in the form of Advance Directives, a Preferred Place to die option and provisions found in the Mental Capacity Act 2005. These findings indicated that government policy discourse is currently prioritising personal choice and human dignity and concepts of rights are being strengthened in an end of life context. The data revealed some evidence of law and policy changes over time which may, in part, have been driven by concerns on the inadequacy of statutory law. For example, the Mental Capacity Act 2005 has extended the remit of individual choice for competent adults through permitting them the right to refuse any, including lifesaving, treatment or the provision of hydration and nutrition to sustain life. To this effect, there is then already, a right to die. But, for some individuals this degree of personal choice is not enough, they demand a *right to request assistance to die*.

The legal petitions of Diane Pretty in 2001 and Tony Nicklinson in 2012 invoked human rights arguments to deliberate the current prohibition on assisted death. The case of *Pretty* was pivotal in that it initiated discussion on the boundaries of human rights principles, recently enshrined in the HRA 1998, suggesting that understandings of rights were fluid, open to interpretation, and could be appropriated in a new context. The case of *Nicklinson* in 2012 interrogated in greater depth the scope of existing human rights, particularly the right to privacy. By this time, rights arguments were gaining traction to the extent that the UK government was confronted with the accusation that the state was acting unlawfully and not in accordance with the rights protected in the ECHR 1950. The cases of *Nicklinson* and *Pretty*,

heard in High Court, and their appeals to the European Court indicate that the prevailing legal narrative is being rigorously challenged through rights arguments that protect the decision-making ability of competent individuals to determine their own death. In this respect the law needs more solid justification to maintain prohibition on assisted death.

This research has, only briefly, examined other countries outside the UK where assisted dying is permitted. In the case of *Carter v. Canada*, discussed in section 5.3, the Supreme Court justified their decision to lift the longstanding prohibition on assisted death through respect for human rights principles. In cases of serious, incurable illness, the judgement found the experience of “intolerable suffering” to entrench upon constitutional rights to “life, liberty and security of the person” (*Carter v. Canada (Attorney General)* [2015] SCC 5). Reflecting on the cases of *Pretty* and *Nicklinson* in the UK, further study of the ways in which human rights discourses, and (violation of) human rights principles have facilitated changes in global legislation is indicated. Examining how, and to what extent, arguments for determining the end of life are framed using human rights discourses in other countries or jurisdictions could inform and complement this research. Extending the parameters of study outside of the UK may also provide much needed suggestions to *why* human rights discourses have become central to the end of life debate.

9.4 Articulating rights explicitly and implicitly to debate assisted death

The topic of assisted death has been debated in the House of Lords on a number of occasions since 1936. Exploration of these debates has helped map the discourses of dying over time and illuminate how an understanding of rights has been developed and used to negotiate arguments in an end of life context. Textual analysis of transcripts of the Bills and debates from 1936, 2003, and 2014 has provided a unique perspective on assisted death. The research findings clearly evidenced the evolving of rights discourses and an increasing use of rights on both sides of the argument, for and against, assisted death. These findings substantiate the hypothesis that rights discourses have become central to the current end of life debate. This is especially significant in such a political forum because the House of Lords debate complicated issues in great depth and have the potential to impact UK law and policy. Analysis of the data did, however, reveal a complex picture; rights were interpreted and used differently in members’ contributions.

The content of all Bills from 1936 to 2014 has remained similar over time. Each Bill has proposed legal change to enable mentally competent, dying individuals release from suffering

through assistance to die at their own request. However, analysis of the debates revealed a historic contrast. Arguments have been developed and the language used to define these arguments has changed. In the 1936 debate, there was minimal articulation of rights, neither explicitly nor implicitly. The case for voluntary euthanasia primarily focused on the value of *compassion* that reflected the prevalent Christian beliefs at that time and this discourse of compassion justified assisting death as a merciful release of suffering. Opposition to this initial Bill centred upon the conflict of medical interest to preserve rather than shorten life, and the sanctity of life which was articulated from the majority perspective as respect for a sovereign God to determine when life should end.

The recent debates since 2003 have transformed the issue of assisted death into one that centres on the balancing of individual liberty rights in end of life decision-making. There was an increasing prioritisation of liberty and respect for freedom of choice over time so that in the 2014 debate, the right to self-determine end of life was the dominant argument for assisted death. Common to the contemporary House of Lords debates, arguments over the extent of liberty rights was revealed as troubling for many members who were cautious or sceptical of protecting individual rights at the expense of the well-being of the community. This reflected the traditional utilitarian approach to law-making in the UK that emphasises the general well-being of citizens and encompasses an obligation by the state to balance the rights of individuals in relation to the rights of other members of society. There was widely expressed concern that a legally established right to die whilst protecting the rights of the dying person may affect the welfare of vulnerable individuals, including the elderly or disabled. However, this was argued on a terrain of rights rather than utilitarian basis, which confirms a shift in ways of thinking about complex issues.

The findings of the data in Chapter 6 clearly demonstrated that arguments in the debates have moved from a discourse of compassion to one of *rights*. A number of arguments used rights discourses *explicitly* to justify their support for legal change, valuing end of life decision-making as a fundamental human right reflecting personal choice, or aligning a right to die with other personal freedoms enshrined in national and international rights mechanisms. Others used rights *implicitly*, emphasising aspects of choice and free will, or focused on specific considerations in the debate such as maintaining human dignity or relieving intolerable suffering. In the 2003 and 2014 debates, arguments both for and against the legalisation of assisted death commonly used rights either explicitly or implicitly to underpin their values and beliefs. The research findings indicated that even those members who disputed or opposed a

right to die, could adopt rights discourses to express their opinion, or use an understanding of legal rights to enhance their position, without necessarily supporting all human rights principles or claims to rights.

Analysis of the debates revealed that most of the Lords, including those in favour of, and opposition to, assisted dying, had become familiar with, and confident in, using what was their interpretation of rights, to argue their positions. On this basis it is apparent that, over time, human rights discourses have become central to the end of life debate, and understandings of *rights* are currently informing the way in which assisted suicide is discussed and thought about in a political forum that is one of the UK's major political institutions. Human rights have come to play a key role in this important forum for debates. Further sociological research could build upon this analysis with regard to other complex issues involving personal freedoms. For example, the House of Lords has debated the laws against homosexuality and legislation relative to the ensuing decriminalisation of homosexuality, on a number of occasions since the initial debate in 1960. Examining the discourses used in the historic debates and comparing this with the more recent 2013 debate on same-sex marriage could map the centrality of rights discourses in a different context. This could then contribute further towards explaining *why* rights discourses resonate at particular historical time periods.

9.5 Campaigning at the end of life through rights-framed approaches

The findings of this research suggest that the prevalence of human rights discourses are not random but arise in response to, and reflect, the social context. The ways in which individuals think about, and give meaning to death and dying can be influenced by social actors who adopt rights discourses strategically, often with a specific purpose. In-depth examination of Dignity in Dying has demonstrated how campaign objectives can be articulated using a rights frame, for the purposes of resonating, mobilising, and holding traction with targeted audiences. As a national organisation, campaigning to change the law on assisted dying and enhance “choice, access and control” at the end of life, Dignity in Dying have shaped perceptions of both the public and the law-makers. Their instrumental use of rights discourses has informed the House of Lords Bills through close collaboration with selected members and this collaboration may have had implications for the terms of these debates. DiD have influenced the sentiment around end of life through constructing and foregrounding discourses that have permeated the public domain and impacted the political debates on assisted death, but their significance has gone largely unremarked.

In a similar manner to the House of Lords debates, analysis of the discourses used by DiD, as a historic organisation, revealed changes over time. The research discovered that there was an, albeit minimal, reference to assisted death as a matter of “elementary human right” (Millard, 1931) during the time the organisation was founded. This appears to have been the first occasion that assisted dying was articulated as having a basis in rights. Contemporary arguments have been strengthened through a more prevalent rights frame that reflects the emerging focus on human rights and their recognition through national and international instruments. This strategic use of rights was evident through analysis of campaign tactics, especially in the run-up to the 2014 House of Lords debate. DiD consciously employed rights discourses that maximised the social context in order that their objectives would appeal to a wider audience.

Different voices within DiD understood rights from both foundational and anti-foundational perspectives. Their vocabulary expressed rights both explicitly and implicitly. The language of the personal narratives less commonly used explicit references to rights but concepts of *choice* and *suffering* advanced their arguments for an assisted death. This informal and familiar language may have greater appeal and more relevance to members of the public who are seriously ill or their families. A number of high profile celebrity and patron contributions did explicitly express a right to determine one’s own death as an issue of fundamental liberty. On occasion, this was aligned with other examples of personal choice already reflected in law, namely sexual orientation and permitted abortion. DiD articulated a “right to choose” through the voices of Patrons and in the personal narratives for the purpose of idealising perceptions of death and dying as matters of personal choice and resonating with members of the public. A constructed right to choose reflects aspirations grounded in individual liberty rights. Human beings are sovereign over their own bodily integrity and, on this basis, there is a fundamental assumption that, acting as rational autonomous agents, they can self-determine their own life and death. A right to choose encompasses concepts of human agency, and this was promoted through the mediated communication of DiD as important at the end of life, and as contributing towards the contemporary understanding of a good death.

Building upon the work of Miller (2010), the data from this case study analysis was used to reflect upon alternative approaches to rights outside of traditional rights-based approaches. The findings largely corroborated DiD as an example of an organisation using a *rights-framed*

approach. There was a demonstrable *strategic* use of rights that was more prevalent in specific campaign contexts. For example, in the more recent campaign period 2014-2016, DiD reconstructed their own interpretations of rights to reflect the aims and aspirations of the organisation and generate wider support. These were expressed on the Home page of the Campaign for Dignity in Dying as a “right to a dignified death”, the “right to a good death” and the “right, when dying, to die well” (DiD, 2016). In contrast to *choice*, the notion of human *dignity* is less contentious. The idea of a dignified death has generic appeal such that no human being would wish for an *undignified* death. Framing dignity as important at the end of life also mirrors the language used in government policy and this may resonate at political level. Strategic use of rights at certain times and the use of rights as a *tool* to serve the official approach of the organisation is indicative of rights-framed approaches developed by Miller (2010) and this was especially evident in the lead up to the 2014 Assisted Dying Bill in the House of Lords. The findings of the case study support Miller’s (2010) hypothesis that there are different ways of understanding and articulating rights outside of rights-based approaches and this has been demonstrated in a new context: to validate and support a claim to the right to die. To build upon these findings, a wider range of case studies outside of development and “right to die” organisations could be selected to expand upon Miller’s (2010) analysis and illustrate other variations of rights-framed approaches.

As the largest UK organisation campaigning to legalise assisted death, the contribution of Dignity in Dying has been influential. Through a rights-framed approach, DiD have used rights discourses to foreground values of choice and control in order to determine the manner and timing of death and avoid an undignified death. Rights discourses used by this organisation were intended to *promote* a right to *die* by enabling individuals to avoid unbearable suffering and experience a good death. A different perspective on dying could be provided through a comparative case study to explore the discourses used by pro-life counterparts, for example the Care Not Killing alliance. There is a possibility that their campaign strategies would use rights discourses to *dispute* an individual right to die or instead highlight the right to *life*. As a recognised “pro-life” organisation, Care Not Killing may adopt alternative strategies to discuss the end of life debate and policy. Their aims and objectives might be grounded in compassionate or faith-based discourses in preference over rights in order to better resonate with their own members and supporter base, many of whom are affiliated with religious organisations.

9.6 Using rights discourses to contemplate death and dying

In a large part of all focus group discussions, there was overwhelming support for individual liberty and dignity that encompassed both an inherent, human dignity and a social or bestowed dignity. Dignity was discussed at length and in-depth, which suggested that it was especially important to this selected group of participants contemplating end of life. The findings of this thesis strongly suggest that dignity is a central component of rights and, although the data from this stage of the research found that rights were not articulated *explicitly*, focus group participants did reference concepts associated with rights *implicitly* throughout their exchanges. Dignity, in particular, informed their perceptions of dying well to the extent that even those participants who had some difficulty describing how they understood the concept of dignity were able to contribute to the discussion through their interpretation of what it meant to lose dignity.

Participant understandings of liberty emphasised respect for personal choice and human agency. These priorities were considered a valid basis for making claims at the end of life. Choice was articulated as an expression of free will and this was largely assumed on the basis of inherently rational human nature. One group, however, did not consider a lack of mental competence, or even a diagnosis of mental illness, as a hindrance to respecting personal choices in end of life decision-making. Another group of participants recognised that, at the end of life, prognosis and symptoms often fluctuate, as does one's state of mind. This complicates and makes it difficult to assess decisional autonomy on the basis of mental capacity. The safeguarding of autonomy in cases of questionable mental capacity directly conflicts with current legal and policy provisions that permit only mentally competent individuals to determine certain aspects of end of life decision-making. In general, focus group participants felt that they were entitled to make their own decisions about the manner and timing of their death. Even in circumstances where mental competence was questionable they had a "right to choose".

Analysis of focus group discussions revealed that an understanding of rights *were* significant to the majority of individuals contemplating end of life. However, these were not generally articulated explicitly as rights. Across all focus groups, there was minimal reference to "rights" as such. Participants did not express their end of life concerns in terms of rights and commonly had difficulty articulating both how they understood a right to something, and what having a right to something would entail. This reluctance to engage with rights *per se* initially appeared inconsistent with earlier findings of the research and, on the surface, suggested that human

rights were not central to this sample of public perceptions of death and dying. However, participants spoke in-depth about concepts that are grounded in human rights discourses: choice, dignity, and, to a lesser extent, suffering. These findings confirmed that focus group participants did use rights discourses as the basis for contemplating issues at the end of life and also when discussing their own experiences of illness or loved ones dying.

It was interesting to compare the language used in the Dignity in Dying personal narratives to focus group discussions on end of life. These two selected groups of actors, both involving members of the public demonstrated a similarity in the ways in which they expressed their concerns. Personal narratives had been curated by DiD and were based on individual experiences of dying or bereavement, but Death Café participants also had a prior and specific interest in discussing death and dying. In common, they tended not to refer explicitly to rights as such, there were minimal references to understanding rights as legal instruments or in conceptual or philosophical terms. Instead, rights discourses were used and interpreted as having localised and immediate meanings, their priorities at the end of life and desires for a good death were *implicitly* expressed using rights discourses, foregrounding individual choice, human dignity and the relief of suffering.

Using a focus group model as part of the research design proved an interesting and accessible method to explore public perceptions on death and dying. This discussion format could be extended to other participant groups. Regular meetings and events are organised by the Multiple Sclerosis Society and the Motor Neurone Disease Association and both these groups have expressed to me their interest in discussing end of life issues, especially when these are articulated as *rights at the end of life*. Personal experience of two local hospices suggests that, in general, they still decline to discuss assisted death with patients and their families. However, there is an indication from end of life practitioners that hospices are gradually recognising the heightened focus on choice in end of life decision-making and this, alongside pressure from a number of patients who do want to decide their own end, is challenging their current practice. Death Cafes have been conducted at some London-based hospices, which suggests that open discussion on death and dying is becoming more common practice, including among those who are seriously ill. This could support further research into public sentiment on end of life.

Concluding remarks

A social constructionist approach has enabled comprehensive insight into how, when, and to what extent rights discourses have been used and understood at the end of life and the purposes for which social actors have employed these. Exploring the social context in light of advances in medical technology, changes in the dying trajectory and the evolving emphasis on patients as healthcare consumers has demonstrated how the landscape of death and dying has shifted over time. Human rights discourses, as articulated by a range of actors, have been proven key to developing and defining the perception of dying in contemporary society. Aspirations of a good death are now commonly grounded in understandings of rights that include respect for individual choice and human dignity.

Analysis of the data confirmed that rights discourses have become central to UK end of life policy and debate, but the interpretation and articulation of rights at different times and by different actors was variable. Analysis of this relationship is complex. Through a sociological understanding of rights, the research findings illuminated the ways in which human rights discourses were being used with regard to death and dying. By understanding different positions on rights, and critically examining human rights discourses, a notion of *rights at the end of life* could be substantiated and embedded in this new context. Further research to explore the reasons *why* rights discourses hold tenure over others, at this specific period in history, could build upon this analysis.

APPENDICES

APPENDIX ONE

Dignity in Dying Campaign Leaflet (November 2011)

Front page

**YOUR
LIFE.
YOUR
DEATH.
YOUR
CHOICE?**

CAMPAIGNING
FOR YOUR
RIGHTS AT THE
END OF LIFE

Dignity
in dying

NO.

**ASSISTED DYING
IS STILL ILLEGAL,
EVEN FOR MENTALLY
COMPETENT, DYING
ADULTS, WHO
ARE SUFFERING
UNBEARABLY. IF YOU
THINK DYING ADULTS
SHOULD HAVE THE
RIGHT TO CHOOSE,
PLEASE JOIN US.**

APPENDIX TWO

Invitation, information letter, consent forms and interview schedule used to recruit and conduct focus groups 2014-15

Invitation to participants September 2014

KINGSTON UNIVERSITY

FACULTY OF ARTS AND SOCIAL SCIENCES

Email sharon.young@kingston.ac.uk Mobile 07939585166

Dear Sir/ Madam,

I would very much appreciate your help with my research on people's attitudes towards end of life issues. I am interested to hear your personal thoughts and experiences on concepts including suffering, human rights, dignity, and personal choice.

The House of Lords have, again, recently debated the issue of assisted dying for seriously ill individuals, and campaigning organisations champion the notion of a "right" to die. However, no in-depth studies have been conducted on the opinion of the wider public and I believe, in view of current campaigns and media focus on medical care and health policies, that it is important to hear your views.

If you would like to join in the study, it would be a group discussion with 6-8 other people who are interested in taking part in research and this would last approximately 1½ hours. I would be there to prompt or ask questions and ensure the discussion ran smoothly with respect for the views of all those taking part. I will record the discussion but all information will be confidential and only used for research purposes.

Times will be arranged to suit those participating and travel expenses would be reimbursed. Refreshments would be provided. If you would like to join the study or have any further questions, please contact me as above.

Yours sincerely,

Sharon Young

PARTICIPANT INFORMATION SHEET

Description of the research:

In an effort to understand what is important to people at the end of their lives and how this is articulated, a group discussion involving members of the public is undertaken.

Data Collection Process:

Your involvement as part of a group discussion with 6-8 participants will last approximately one and a half hours. I would record our discussion using an audio-recorder and then write up it up fully afterwards, deleting the recording immediately. You are welcome to request a written summary of the discussion for your own private use.

Intended Publication:

The findings of the study will form part of my PhD thesis and may be used in subsequent journal articles, conference presentations or as teaching materials. Your name and personal information will not be identifiable in any of these publications unless you choose not to remain anonymous. This is done by signing a separate section at the bottom of the consent form.

Obtaining Consent

You are under no obligation to take part in the study and of course you are free to reconsider or leave at any time without explanation. All aspects of the discussion will be confidential and in reporting the study, no information will be released to identify individual comments unless you have signed to agree to be named. In order to give your written consent please read and then sign the accompanying consent form when you come to the discussion.

Afterwards

I hope you enjoy participating in the study and feel that it has been conducted in a professional manner. If you have any comments, feedback or complaints on the study, please contact either me or my Director of Studies Dr Hannah Miller.

Contact details:

Chief Investigator: Sharon Young sharon.young@kingston.ac.uk

Director of Studies: Dr Hannah Miller H.Miller@kingston.ac.uk

Kingston University, Penrhyn Road, Kingston, Surrey KT1 2EE

WRITTEN CONSENT TO PARTICIPATE IN A RESEARCH STUDY

Statement by participant

- I confirm that I have read and understood the information sheet/letter of invitation for this study. I have been informed of the purpose, risks, and benefits of taking part.
- I understand what my involvement will entail and any questions have been answered to my satisfaction.
- I understand that my participation is entirely voluntary, and that I can withdraw at any time without prejudice or the need for explanation.
- I consent to being recorded with an audio-recorder on the conditions that the original and transferred data is deleted on completion of the thesis.
- I understand that all information obtained will be confidential and have been informed that data gathered for the study will be anonymised unless I have signed the statement below.
- Contact information has been provided should I (a) wish to seek further information from the investigator at any time for purposes of clarification (b) wish to make a complaint.

Participant's Signature _____ Date _____

Statement by investigator

- I have explained this project to this participant without bias and I believe that the consent is informed and that he/she understands the implications of participation.

Signature of investigator _____ Date _____

Anonymity

- I do not wish to remain anonymous and consent to be named when quoting from or in writing about the discussion.

Participant's signature _____ Date _____

FOCUS GROUP DISCUSSION FORMAT

- On arrival, people will be greeted by myself and have opportunity to order refreshments. Travel expenses will be reimbursed and consent forms explained where necessary and signed. Participants will also be asked to fill out the following information in the format:

First name: _____ Gender: M / F (Please circle)

Profession: _____ Age: _____

Do you have a serious illness? Y / N (Please circle)

- After ensuring that everyone is seated comfortably and has everything that they need with them, I will sit around the table on the same level with participants in a position I feel is appropriate.
- INTRODUCTION: Thank you all for coming. Welcome to everyone. I would like to start by introducing myself and saying a little about what we will be doing today. My name is Sharon Young; I have a background in Physiotherapy working in hospitals, clinics and the community. A few years ago I had a career change and started studying Human Rights and Politics at Kingston University- a bit different I know- but it combines my interest in people, their wellbeing and how they interact with each other in society. Today we will be having an open discussion lasting around one and a half hours. In this time I would like everyone to have an opportunity to express their ideas and thoughts. On this basis it is important that we respect each person's view and experiences and that our discussion is confidential so that the things people share, ideally remain within this room. I will be recording this session with the voice recorder so that I can listen to the discussion again later and write it up accurately. When I am writing it up, all comments will be anonymous and it will not be shown to anyone else. If you would like a summary of our discussion, or have any other feedback about today then please phone or email me- you have my contact details.
- OPEN QUESTION: I would like to start by sharing this quote by Lisa Cooke and hearing your opinions about it;

“I like to think that I have lived my life with dignity and I would also like to be able to die with dignity”.

(Lisa Cooke, 2013)

- PROMPTS may be used depending on the direction of the conversation, to reiterate and/or probe a particular point raised or in an attempt to include all participants.

- KEY QUESTIONS: I would like to hear what you think about the following concepts;
 1. The “right” to die
 2. Personal choice
 3. Suffering

- CLOSING QUESTION: It is time to bring our discussion to a close now, but first I would like to draw your attention back to some of the things we have been talking about and ask each of you what you consider to be most important at the end of your life?

- Thank you to everyone for participating in the discussion today, it has been really helpful to hear all your views and opinions. We have finished the session now but I am happy to take any questions or comments you may have and do feel free to mention anything you feel you didn't get a chance to say earlier.

APPENDIX THREE

Political allegiances of House of Lords Members targeted for lobby in 2014 on the basis of their positions on assisted dying

(Reproduced by kind permission of Tom Davis, Dignity in Dying 2016)

Position	Labour	Conservative	Crossbencher	Lib Dem	Other	Total
Immutably Opposed	18	35	35	12	31	131
Opposed	35	61	28	11	4	139
Likely Opposed	8	16	7	1	1	33
Neutral or WNV	2		3	2		7
Unknown	17	33	19	18	3	90
Likely Supportive	30	20	16	9	2	77
Supportive	89	49	42	38	5	223
Strongly Supportive	20	3	20	6	3	52
Total	219	217	170	97	49	752

Total Peers (c. June 2014) organised by specific position on assisted dying.

Position	Labour	Conservative	Crossbencher	Lib Dem	Other	Total
Opposed total	61	112	70	24	36	303
Unknown / Neutral	19	33	22	20	3	97
Supportive	139	72	78	53	10	352
Total	219	217	170	97	49	752

Total Peers organised by general position on assisted dying.

Position	Labour	Conservative	Crossbencher	Lib Dem	Other	Total
'Target' Peers	166	121	107	74	14	482

Total Peers included on targeted lobbying list (i.e. excluding confirmed and immutable opponents).

APPENDIX FOUR

Dignity in Dying Campaign Newsletter Issue 3 of 3, 2014



Page 5



Page 16

6

TRACY SNELLING: AN "UNDIGNIFIED DEATH"

BY STEVE RILEY-SNELLING

My wife Tracy was just 49, highly intelligent and a member of Mensa. Tracy loved her life, she loved me, she loved her son and she loved her job. She had everything to live for and she did not want to die.

In the run-up to Christmas 2012, Tracy was diagnosed with stomach cancer. Only about 20% of people with stomach cancer are able to have surgery to try to cure their cancer and we were therefore pleased to learn that it should be operable. There was some evidence that the cancer had spread but we were reassured that eight cycles of chemotherapy should both shrink the stomach tumour and address the spread.

In March, we celebrated when we were told the chemo was working. Three months later we were devastated when told it hadn't worked; the cancer had spread, it was very aggressive, the drugs hadn't worked and it was game over.

We were madly in love but never got round to getting married. On our wedding day Tracy looked the picture of health but the cancer was already taking its toll. None of our guests realised she had been so

poorly the night before that we had had to call the duty doctor to attend her, or that she could eat nothing and had vomited no fewer than 10 times on the day. Needless to say, there was no honeymoon and, very shortly after the wedding, Tracy's condition deteriorated at a rapid rate.

Within a week of the wedding Tracy was hooked up to a syringe driver which drip-fed her a cocktail of morphine and anti-sickness drugs 24 hours a day – neither of which gave effective relief. I am immensely grateful to the nurses who attended her twice daily but, whatever the medical profession may say, palliative care has its limitations. Pain control is relatively straightforward but managing the symptoms of stomach cancer is not.

Tracy was denied the choice to decide how and when she died. Because this country denies its people the right to self-determination in death, Dignitas was arguably the only option. Tracy applied for membership but we soon came to realise that, unless you go there too soon, it is too late.

So I watched my beautiful, kind, intelligent wife slowly deteriorate day by day; she couldn't eat, she could hardly drink without vomiting.

she couldn't walk more than a few steps without becoming breathless, she developed a blood clot and suffered constant pain, nausea and constipation, despite the drugs.

Nothing in my worst nightmares could have prepared me for Tracy's death for more than five hours she endured the most awful suffering one could possibly imagine until she finally passed away screaming as I held her in my arms. Four nurses in attendance could do nothing to alleviate her suffering they could only clear up the continuous and endless stream of vomit and blood as she lay on her side.

Had the law allowed, the nurses could have given Tracy medication to put an end to it, but their hands were tied. After three agonising hours, I pleaded for plan B; there was no Plan B. To lose such a wonderful person to cancer was devastating; to witness her suffer such a violent death was heart-breaking.

Why do we force our loved ones to die in pain, suffering and humiliation? My beautiful wife, along with countless others in this country, was denied choice at the end of life.

Steve has bravely shared the story of his wife's death to the TV, radio and the papers. Personal testimonies such as these, whilst difficult, are a fundamental part of the campaign. If you have a personal story to share please contact:

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BIBLIOGRAPHY

Airedale NHS Trust v Bland [1993]1 All ER 821 HL Available at:

<http://www.globalhealthrights.org/wp-content/uploads/2013/01/HL-1993-Airedale-NHS-Trust-v.-Bland.pdf> (Accessed 17.03.16)

Aries, P. (1974) *Western attitudes toward death: from the Middle Ages to the present*. London: John Hopkins University Press

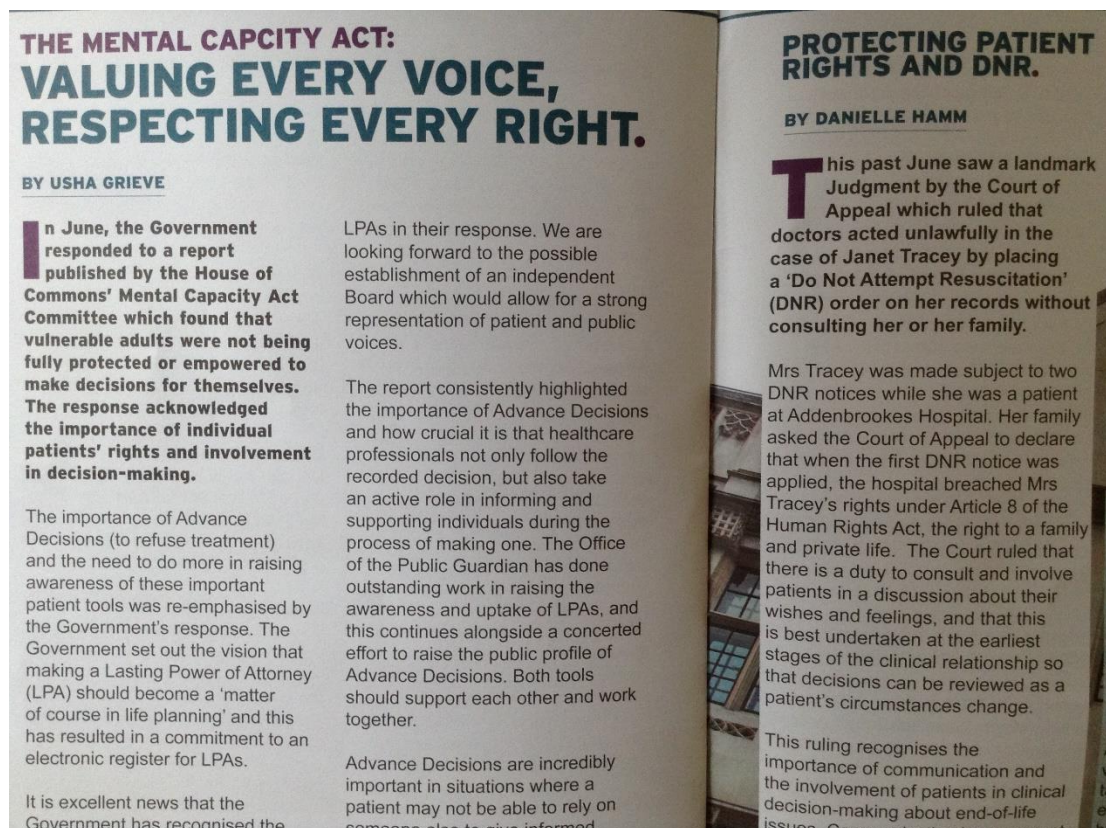
Aries, P. (1981) *The Hour of Our Death*. London: Allen Lane

Assisted Dying Bill (2014) Available at:

<http://www.publications.parliament.uk/pa/bills/lbill/2014-2015/0006/15006.pdf> (Last accessed 17.03.16)

Assisted Dying for the Terminally Ill Bill (2006) Available at:

<http://www.publications.parliament.uk/pa/ld200506/ldbills/036/06036.i.html> (Last accessed 17.03.16)



Assisted Suicide (Scotland) Bill (2013) Available at:

<http://www.scottish.parliament.uk/S4/Bills/Assisted%20Suicide/b40s4-introd.pdf> (Accessed 21.05.15)

Auerbach, S.M. (2001) "Do patients want control over their own healthcare?" *Journal of Health Psychology*. Vol 6(2) pp191-203

Bagaric, M., Allan, J. (2006) "The Vacuous Concept of Dignity". *Journal of Human Rights* Vol 5 pp257-270

Barbar, R. Kitzinger, J. (Eds) (1999) *Developing Focus Group Research, Politics, Theory and Practice*. London: Sage

Barclay, S., Birklund, T. (1998) "Law, Policymaking and the Policy Process: Closing the Gaps". *Policy Studies Journal*. Vol 26(2) pp227-243

Barnes, B. (2000) *Understanding Agency*. London: Sage

Battin, M. van der Heide, A. Ganzini, L. van der Wal, G. Onwuteaka-Philipsen, B. (2007) "Legal physician assisted dying in Oregon and the Netherlands: evidence concerning the impact of patients in "vulnerable" groups". *Journal of Medical Ethics* Vol 33 (10) pp591-597

Battin, M. (1994) *The Least Worst Death*. Oxford: Oxford University Press

BBC News (2012) "Tony Nicklinson's legal fight for right to die" [online] Available at: <http://www.bbc.co.uk/news/uk-england-wiltshire-19341571> (Accessed 07.01.16)

Belden Fields, A. (2003) *Rethinking Human Rights for the New Millennium*. UK: Palgrave MacMillan

Bell, N. (1996) "Responsibilities and rights in the promotion of health". *Social Science and Medicine*. Vol 43(5) pp775-782

Bentham, J. (1834) "Anarchical Fallacies" in Bowring, J. (Ed) (1987) *The works of Jeremy Bentham*. London: Elibron Classics

Birenbaum-Carmeli, Bannerjee, Taylor (2006) "All in the family" *Social Science and Medicine*. Vol 63 pp2153-2162

BMA (2016) "End of life care and physician assisted dying". Available at:

<http://www.bma.org.uk/working-for-change/improving-and-protecting-health/end-of-life-care> (Accessed 27.04.16)

- BMA (2012) BMA Policy "Assisted dying". Available at: <https://www.bma.org.uk/advice/employment/ethics/ethics-a-to-z/physician-assisted-dying> (accessed 07.07.16)
- Bobbio, N. (1996) *The Age of Rights*. UK: Polity Press
- Borgstrom, E. and Walter, T. (2015). "Choice and compassion at the end of life: a critical analysis of recent English policy discourse". *Social Science & Medicine*, 136, pp99-105.
- Bradburn, J. (2003) "Developments in user organisations". In Monroe, B., Oliviere, D. (Eds) *Patient participation in palliative care: A voice for the voiceless*. Oxford: Oxford University Press pp22-38
- British Institute of Human Rights (BIHR) (2016) "End of Life Care and Human Rights: A practitioner's guide" Available at: <https://www.bihar.org.uk/eolchumanrights> (Accessed 09.12.16)
- British Sociological Association (2002) "Statement of Ethical Practice for the British Sociological Association". Available at: <http://www.britisoc.co.uk/NR/rdonlyres/801B9A62-5CD3-4BC2-93E1-FF470FF10256/0/StatementofEthicalPractice.pdf> (Accessed 28.01.16)
- Bruce, S. (2013) "Post-Secularity and Religion in Britain: An Empirical Assessment". *Journal of Contemporary Religion* Vol 28(3) pp369-384.
- Bryman, A. (2008) (3rd Ed) *Social Research Methods*. Oxford: Oxford University Press
- Burchardt, T., Evans, M., Holder, H. (2014) "Public Policy and Inequalities of Choice and Autonomy". *Social Policy and Administration* Vol 49(1) pp44-67
- Burr, V. (1998) "Overview: Realism, Relativism, Social Constructionism and Discourse" in Parker, I. (1998) (Ed) *Social Constructionism, Discourse and Realism*. London: Sage
- Byrne, P. (1997) *Social Movements in Britain*. London: Routledge
- Campbell, C. (1996) "Suffering, Compassion and Dignity in Dying". *Duquesne Law Review* Vol 35 pp109-124
- Campbell, T. (2006) *Rights: A Critical Introduction*. London: Routledge
- Carr, D. (2003) "A "Good Death" for Whom? Quality of Spouse's Death and Psychological Distress among Older Widowed Persons" *Journal of Health and Social Behavior* Vol. 44 (2) pp 215-232
- Carel, H. (2008) *Illness: The Cry of the Flesh*. Durham: Acumen

- Carter v. Canada (Attorney General), [2015] SCC 5 (6th February, 2015) Available at: <http://scc-csc.lexum.com/scc-csc/scc-csc/en/item/14637/index.do> (Accessed 22.04.15)
- Chong, D., Druckman, J.N. (2007) "A Theory of Framing and Opinion Formation in Competitive Elite Environments". *Journal of Communication* Vol 57(1) pp99-118
- Chapman, J. (2014) "Carey: I've changed my mind on right to die" (Daily Mail [online] Available at: <http://www.dailymail.co.uk/news/article-2689295/Carey-lve-changed-mind-right-die-On-eve-Lords-debate-ex-Archbishop-dramatically-backs-assisted-death-law.html>) (Accessed 02.12.15)
- Chen, E., Riffin, C., Cary Reid, M., Adelman, R., Warmington, M., Mehta, S., Pillemar, K. (2014) "Why is High-Quality Research on Palliative Care So Hard To Do? Barriers To Improved research from a Survey of Palliative Care Researchers". *Journal of Palliative Medicine*. Vol 17(7) pp782-787
- Chochinov, H.M., Hack, T., McClement, S., Kristjanson, L., Harlos, M. (2002) "Dignity in the terminally ill: a developing empirical model". *Social Science and Medicine* Vol 54 (3) pp433-445
- Chochinov, H.M., Wilson, K., Enns, M., Mowchun, N. et al (1995) "Desire for Death in the Terminally Ill". *American Journal of Psychiatry*. Vol 152(8) PP1185-1191
- Choice in End of Life Care (2015) "What's important to me? A review of choice in end of life care. Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/407244/CHOICE_REVIEW_FINAL_for_web.pdf (Accessed 28.03.2015)
- Clark, D., Seymour, J. (1999) *Reflections on Palliative Care*. UK: Open University Press
- Coggon, J. (2010) "Assisted dying and the context of the debate: medical law v. "end of life" law". *Medical Law Review* Vol 18 pp541-563
- Coggon, J. (2006) "Could the right to die with dignity represent a new right to die in English law?" *Medical Law Review*. Vol 14 pp219-237
- Collins English Dictionary (8th Ed) (2012) Glasgow: Harper Collins
- Commission on Assisted Dying (2012) "The Commission on Assisted Dying". Available at: http://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_1_web_single-NEW_.pdf?1328113363 (Accessed 19.01.12)
- Constitution Act (1982) "Canadian Charter of Rights and Freedoms" Available at: <http://laws-lois.justice.gc.ca/eng/const/page-15.html> (Accessed 04.02.16)

- Cowan, J., Dembour, M.B., Wilson, R. (Eds) (2001) *Culture and Rights*. Cambridge: Cambridge University Press
- Cranston, M. (1973) *What are Human Rights?* London: The Bodley Head Ltd
- Criminal Justice Act (1967) "Criminal Justice Act 1967" Available at: http://www.legislation.gov.uk/ukpga/1967/80/pdfs/ukpga_19670080_en.pdf (Accessed 21.04.15)
- Crown Prosecution Service (CPS) (2014) "Assisted suicide" Available at: http://www.cps.gov.uk/publications/prosecution/assisted_suicide.html (Accessed 01.12.14)
- Dalton, D. (2007) *Building National Campaigns*. Great Britain: Oxfam
- Danyliv, A., O'Neill, C. (2015) "Attitudes towards legalising physician provided euthanasia in Britain: The role of religion over time". *Social Science and Medicine* Vol 128 pp52-56
- Davie, G. (2014)(2nd Ed) *Religion in Britain: A persistent paradox*. [online access]
- Death Café (2014) "Death Café". Available at: <http://www.deathcafe.com>
- Death with Dignity National Centre (2014) "Death with Dignity: the Laws and how to access them" Available at: <http://www.deathwithdignity.org/access-acts> (Accessed 02.12.14)
- Dees, M.K., Vernooij-Dassen, M.J., Dekkers, W., Vissers, K., van Weel, C. (2011)" 'Unbearable suffering': a qualitative study on the perspectives of patients who request assistance in dying" *Journal of Med Ethics* (37) pp727-734
- Della Porta, D, Diani, M. (2nd Ed) (2006) *Social Movements: An Introduction*. Oxford: Blackwell
- Dembour, M-B. (2010) "What are Human Rights? Four Schools of Thought". *Human Rights Quarterly*. Vol 32(1) pp1-20
- Den Uyl, D., Rasmussen, D. (2001) "Ethical Individualism, Natural Law and the Primacy of Natural Rights" in Paul, E., Miller, F., Paul, J. (2001) (Eds) *Natural Law and Modern Moral Philosophy*. Cambridge: Cambridge University Press
- Denzin, N. Lincoln, Y. (1998) (Eds) *Collecting and Interpreting Qualitative Materials*. London: Sage
- DeSmith, Woolf and Jowell's (1999) *Principles of Judicial Review*. London: Sweet and Maxwell.
- Dickson-Swift, V. James, E. Liamputtong, P. (2008) *Undertaking Sensitive Research in the Health and Social Sciences*. Cambridge: Cambridge University Press

- DiD a (2016) "Welcome" Available at: <http://www.dignityindying.org.uk/> (Accessed 28.04.16)
- DiD b (2016) "Support Us" Available at: <https://www.dignityindying.org.uk/support-us/what-is-campaign-dignity-in-dying/> (Accessed 28.04.16)
- DiD a (2014) "Home" Available at <http://www.dignityindying.org.uk/> (Accessed 13.05.14)
- DiD b (2014) "About us" Available at: <http://www.dignityindying.org.uk/about-us/> (Accessed 18.06.14)
- DiD c (2014) "Assisted dying" Available at: <http://www.dignityindying.org.uk/assisted-dying/> (Accessed 18.09.14)
- DiD d (2014) "About us/ Patrons" Available at: <http://www.dignityindying.org.uk/about-us/patrons/?orderby=title> (Accessed 13.05.14)
- DiD Trustees Report (2015) "Dignity and Choice in Dying, Report and Financial Statement" Available at: <http://www.dignityindying.org.uk/wp-content/uploads/2016/05/DID-2015-report-and-financial-statements.pdf> (Accessed 17.06.16)
- DOH Strategy (2008) "End of Life Care Strategy" Available at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136431/End_of_life_strategy.pdf (Accessed 28.03.2015)
- Donnelly, Jack. (2007) "The relative universality of human rights." *Human Rights Quarterly*. Vol 29(2) pp 281-306.
- Donnelly, J. (2003) (3rd Ed) *Universal Human Rights in Theory and Practice*. London: Cornell University Press
- Dopson, S. (2009) "Changing forms of managerialism in the NHS" in Calnan, M. and Gabe, J. (Eds) (2009) *The New Sociology of the Health Service*. London: Routledge pp37-55
- Douzinis, C. (2000) *The End of Human Rights*. Oxford: Hart Publishing
- Dowbiggin, I. (2007) *A Concise History of Euthanasia*. Plymouth: Rowman and Littlefield Publishers, Inc
- Doyal L. and Doyal, L. (1999) "The British National Health Service: A Tarnished Moral Vision?" *Health Care Analysis* Vol 7 pp363-376
- Dworkin, G. (1998) "The Nature of Medicine". In Dworkin G., Frey, R.G., Bok, S. *Euthanasia and Physician Assisted Suicide*. pp6-16 UK: Cambridge University Press
- Dworkin, R. (1993) *Life's Dominion*. New York: Vintage Books

- Dworkin, R. (1977) *Taking Rights Seriously*. London: Duckworth
- ECHR European Convention on Human Rights (1950) Available at: http://www.echr.coe.int/NR/rdonlyres/D5CC24A7-DC13-4318-B457-5C9014916D7A/0/CONVENTION_ENG_WEB.pdf (Accessed 19.11.12)
- Elias, N. (1985) *The Loneliness of the Dying*. Oxford: Basil Blackwell
- Elston, M.A. (2009) "Remaking a trustworthy medical profession in 21st Century Britain" in Calnan, M. and Gabe, J. (Eds) (2009) *The New Sociology of the Health Service*. London: Routledge pp17-36
- Emanuel, E.J. et al (1996) Euthanasia and Physician Assisted Suicide: Attitude and experiences of oncology patients, oncologists and the public. *The Lancet*, 347 (9018) pp1805-10
- Etzioni, A., Brodbeck, L. (2012) "Rights and Responsibilities: the Intergenerational Covenant" *Journal of Comparative Social Welfare* Vol 28(2) pp113-117
- Etzioni, A. (1997) *The New Golden Rule. Community and Morality in a Democratic Society*. London: Profile Books
- Equality Act (2010) "Gender and Equality Act" Available at: http://www.legislation.gov.uk/ukpga/2010/15/pdfs/ukpga_20100015_en.pdf (Accessed 20.03.13)
- Fairclough, N. (2000) *Discourse and Social Change*. Cambridge: Polity Press
- Feinberg, J. (1980) *Rights, Justice and the Bounds of Liberty*. Princeton: Princeton University Press
- Freeden, M. (1991) *Rights*. Buckingham: Open University Press
- Freeman (2011) (2nd Ed) *Human Rights*. Cambridge: Polity Press
- Field, D., Clark, D., Corner, J., Davis, C. (Eds) (2001) *Researching Palliative Care*. Buckingham: Open University Press
- Foucault, M. (1977) (Translation Alan Sheridan) *Discipline and Punish: The Birth of the Prison*. Middlesex: Penguin
- Foucault, M. (1973) (Translation Alan Sheridan) *The Birth of the Clinic*. London: Tavistock
- Frezzo, M. (2014) *The Sociology of Human Rights*. London: Polity
- Friends at the end (FATE)(2012)"Home" Available at: <http://www.friends-at-the-end.org.uk/> (Accessed 10.12.12)

- Ganzini, L., Goy, E., Dobscha, S. (2008a) Why Oregon Patients request assisted dying: family members' views. *Journal of General Internal Medicine*. Vol 23(2)pp154-7
- Ganzini, L., Goy, E., Dobscha, S. (2008b) "Prevalence of depression and anxiety in patients requesting physician aid in dying. A cross sectional survey." *British Medical Journal*. Vol 337a 1682
- General Medical Council *a* (2014) "Consent guidance" Available at: http://www.gmc-uk.org/guidance/ethical_guidance/consent_guidance_common_law.asp (Accessed 01.12.14)
- General Medical Council *b* (2014) "Response to DPP's consultation on Assisted Suicide" Available at: <http://www.gmc-uk.org/guidance/5643.asp> (Accessed 01.12.14)
- General Medical Council (2013) "Duties of a doctor". Available at: http://www.gmc-uk.org/guidance/good_medical_practice/duties_of_a_doctor.asp (Accessed 21.11.13)
- General Medical Council (2002) "Treatment and care towards the end of life: good practice in decision-making". Available at: www.gmc-uk.org/guidance/ethical_guidance/end_of_life_care.asp (Accessed 13.11.16)
- Gewirth, A. (1996) *The Community of Rights*. Chicago: University of Chicago Press
- Gewirth, A. (1984) "The Epistemology of Human Rights" in *Social Philosophy and Policy* vol1 (2) pp1-24
- Glendon, M. (1991) *Rights Talk*. New York: Free Press
- Gomez, B., Calanzani, N., Higginson, I J (2010) "Local preferences and place of death in regions within England" Report. Available at: http://www.endoflifecare-intelligence.org.uk/resources/publications/lp_and_place_of_death (Accessed 27.10.16)
- Goodale, M., Engle Merry, S. (2007) (Eds), *The Practice of Human Rights – Tracking Law between the Global and the Local*: Cambridge, Cambridge University Press
- Gross v Switzerland* (2014) 58 EHRR 7. Summary available at: http://www.echr.coe.int/Documents/FS_Euthanasia_ENG.pdf (accessed 23.01.17)
- Gustafson, D. (2007) "A Good Death" *Journal of Medical Internet Research*. Vol 9(1)
- Haas v Switzerland* (2011) 53 EHRR 33. Summary available at: http://www.echr.coe.int/Documents/FS_Euthanasia_ENG.pdf (accessed 23.01.17)
- Habermas, J. (1990) *Moral Consciousness and Communicative Action*. UK: Polity Press

- Hallam, E. Hockey, J. Howarth, G. (1999) *Beyond the Body: Death and Social Identity*. London: Routledge
- Harrison, S., McDonald, R. (2008) *The Politics of Healthcare in Britain*. London: Sage
- Hart, B., Sainsbury, P., Short, S. (1998) "Whose dying? A sociological critique of the "good death"". *Mortality: Promoting the Interdisciplinary Study of death and dying* Vol 3(1) pp65-77
- Hart, H.L.A. (1958) Positivism and the Separation of Law and Morals. *Harvard Law Review* Vol 71(4) pp593-629
- Hastings, A. (1998) "Connecting Linguistic Structures and Social Practices: a discursive approach to policy analysis". *Journal of Sociology and Politics* Vol 27(2) pp191-211
- Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., Wilkinson, C. (2013) "Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying". *Palliative Medicine*. Vol 27(1) pp13-26
- Heywood, A. (2007) (4th Ed) *Political Ideologies: an Introduction*. UK: Palgrave MacMillan
- Ho, R., Chantagul, N. (2015) "Support for Voluntary and Non-voluntary Euthanasia: What Roles Do Conditions of Suffering and the Identity of the Terminally Ill Play?" *Omega-Journal of Death and Dying* Vol 70(3) pp251-277
- Hoffman, D., Rowe, J. (2010) (3rd Ed) *Human Rights in the UK*. UK: Pearson
- Homicide Act (1957) "Homicide Act" Available at:
<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasyd/86/4090902.htm>
 (Accessed 01.02.13)
- House of Lords (2016) "The role and work of the House of Lords" Available at:
<http://www.parliament.uk/about/faqs/house-of-lords-faqs/role/> (Accessed 06.02.16)
- House of Lords (2016) "Lords by party, type of peerage, and gender". Available at:
<http://www.parliament.uk/mps-lords-and-offices/lords/composition-of-the-lords/> (Accessed 06.02.16)
- House of Lords (2014) "Assisted Dying Bill". Available at:
<http://www.publications.parliament.uk/pa/ld201415/ldhansrd/text/140718-0001.htm> (Last accessed 17.03.16)
- House of Lords (2006) *Official Report 5th Series. Parliamentary debates. Lords (2005-2006)* Vol 681 col 1184-1296. UK: Stationery Office

House of Lords (2005) "Select Committee Report on the Assisted Dying for the Terminally Ill Bill". Available at:

<http://www.publications.parliament.uk/pa/ld200405/ldselect/ldasyd/86/86i.pdf> (Accessed 05.07.16) Vol I

House of Lords (2003) *Official Report 5th Series. Parliamentary Debates. Lords (2002-3)* Vol 648 col 1568-1690. UK: Stationery Office

House of Lords (1969) "Voluntary Euthanasia Bill" [H.L.] Available at:

<http://hansard.millbanksystems.com/lords/1969/mar/25/voluntary-euthanasia-bill-hl>

(Accessed 18.06.15)

House of Lords (1950) "Voluntary Euthanasia Bill" [H.L.] Available at:

<http://hansard.millbanksystems.com/lords/1950/nov/28/voluntary-euthanasia> (Accessed

18.06.15)

House of Lords (1936) *Official Report 5th Series. Parliamentary Debates. Lords (1936-1937)* Vol 102 col 466-506. London: Her Majesty's Stationery Office

Howarth, G. (2007) *Death and Dying: A sociological introduction*. Cambridge: Polity Press

Human Rights Act (1998) "Human Rights Act". Available at:

<http://www.legislation.gov.uk/ukpga/1998/42/contents> (Accessed 04.10.13)

Hynes, P., Lamb, M., Short, D., Waites, M. (2012) (Eds) "Special Issue: The Sociology of Human Rights". *Sociology*. Vol 46(5) pp786-796

Hynes, P., Lamb, M., Short, D., Waites, M. (2011) (Eds) *Sociology and Human Rights: New Engagements*. London: Routledge (reproduced from *International Journal of Human Rights*. Vol 14, issue 6).

Hynes, P., Lamb, M., Short, D., Waites, M. (2010) "Sociology and human rights: confrontations, evasions and new engagements". *International Journal of Human Rights*. Vol 14(6) pp811-832

ILO (2016) "About the ILO". Available at: <http://www.ilo.org/global/about-the-ilo/lang--en/index.htm> (Accessed 21.12.16)

Ingleton, C., Gott, M., Gardiner, C. (2013) Autonomy and Choice in Palliative Care: Time for a New Model? *Journal of Advanced Nursing* Vol 70(5) pp 1020-29

Jacobsen, N. (2009) "A taxonomy of dignity: a grounded theory study". *International Health and Human Rights*. Vol 9(3)

- Jacobsen, N. (2007) "Dignity and Health: A Review". *Social Science and Medicine*. Vol 64(2) pp292-302
- Jeffrey, D. (2009) *Against Physician Assisted Suicide*. UK: Radcliffe Publishing
- Jennings, G. (1996) *The Perversion of Autonomy: The Proper Uses of Coercion and Constraints in a Liberal Society*. NY: Free Press
- Jewell, D. (Ed) (2009) Our debt to those who are dying: the UK medical establishment should reconsider its stance on assisted suicide. *British Journal of General Practice* 59 (568) pp809-812
- Johansen et al (2005) "Attitudes towards and wishes for euthanasia in advanced cancer patients at a palliative medical unit". *Palliative Medicine*. Vol 19 p454
- Kant, Immanuel ([1775-80] 1963) *Lectures on Ethics*, translated by Louis Infield. New York: Harper & Row, pp. 147-154.
- Kant, Immanuel ([1724-1802] 1996) *The Metaphysics of Morals*, edited by Mary Gregor. Cambridge: Cambridge University Press
- Kateb, G. (2011) *Human Dignity*. London. The Bellknap Press
- Keating, H. (2016) "Compassionate killing-or murder?" Available at <https://www.youtube.com/watch?v=rwWTCI3I19U> (Accessed 13.12.16)
- Kellehear, A. (2009) "On dying and human suffering". *Palliative Medicine*. Vol 23(5) pp388-397
- Kellehear, A. (2008a) "Dying as a social relationship: A sociological review of debates on the determination of death". *Social Science and Medicine*. Vol 66(7) pp1533-1544
- Kellehear, A. (2008b) "Modern death-who cares?" *Soundings*. Spring issue 38 pp82-87
- Kemp, N.D.A. (2002) "Merciful Release" *The History of the British Euthanasia Movement*. Manchester: Manchester University Press.
- Keown, J. (2002) *Euthanasia, Ethics and Public Policy*. UK: Cambridge University Press
- Kincheloe, J.L., McLaren, P. (2002) "Rethinking Critical Theory and Qualitative Research" in Zou, Y., Trueba, E.T. (Eds) *Ethnography and Schools: Qualitative Approaches to the Study of Education*. Oxford: Rowman and Littlefield Publishers pp87-138
- Kingdon, J. (2003) (2nd Ed) *Agendas, Alternatives and Public Policies*. New York: Longman
- Klein, R. (2010a) "The Eternal Triangle: Sixty Years of the Centre-Periphery Relationship in the National Health Service". *Social Policy and Administration*. Vol 44 (3) pp285-304

- Klein R. (2010b) (6th Ed) *The New Politics of the NHS*. Oxford: Radcliffe
- Koch v Germany* (2013) 56 EHRR 6. Summary available at:
http://www.echr.coe.int/Documents/FS_Euthanasia_ENG.pdf (accessed 23.01.17)
- Koenig, B.A., Gates-Williams, J. (1995) "Understanding cultural differences in caring for dying patients". *Western Journal of Medicine* 163 pp244-249
- Kohn, D., Steeves, R. (1996) "An understanding of suffering grounded in clinical practice and research" in Ferrell, B.R. (1996) *Suffering*. London: Jones and Bartlett Publishing International
- Kreuger, R. (1998a) *Moderating Focus Groups*. London: Sage
- Kreuger, R. (1998b) *Developing Questions for Focus Groups*. London: Sage
- Law Pages (2015) "Thelawpages.com" Available at: <http://www.thelawpages.com/court-cases/Kevin-James-Howe-12116-1.law> (Accessed 24.04.2015)
- Lawton, J. (2000) *The Dying Process: Patients' Experiences of Palliative Care*. London: Routledge
- Leadership Alliance for the Care of Dying People LACDP (2014) "Once chance to get it right"
 Available at:
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf (accessed 14.11.16)
- Lee, R. (1993) *Doing Research on Sensitive Topics*. London: Sage
- Lee, A. M., & Lee, E. B. (1972). *The fine art of propaganda*. Octagon Press, Limited.
- Lewis, J. (2001) *Constructing Public Opinion*. NY: Columbia University Press
- Liverpool Care Pathway (LCP) (2013) "More Care, Less Pathway: a review of the LCP" July 2013
 Available at: <https://www.gov.uk/government/publications/review-of-liverpool-care-pathway-for-dying-patients> (accessed 27.10.16)
- Locke, John. [1689-90] (1970) *Two Treaties of Government*. Cambridge: Cambridge University Press
- Marshall, Thomas H. (1950) *Citizenship and social class*. Vol. 11. Cambridge (1950)
- Mak, Y., Elwyn, G. (2005) "Voices of the terminally ill: uncovering the meaning of the desire for euthanasia". *Palliative Medicine*. Vol 19 pp343-350
- Maritain, J. (1971) (Trans. Doris Anson) *The Rights of Man and Natural Law*. New York: Gordian.

- McInerney, F. (2000) "Requested Death: a new social movement" *Social Science and Medicine* Vol 50 pp137-154
- McCormack, R., Clifford, M., Conroy, M. (2012) "Attitudes of UK doctors towards euthanasia and physician-assisted suicide: A systematic literature review" *Palliat Med.* Vol. 26 (1) pp 23-33
- Mellor, P. (1993) "Death in high modernity: the contemporary presence and absence of death" in Clark, D. (1993) (Ed) *The Sociology of Death*. Oxford: Blackwell pp11-30
- Mental Capacity Act (2005) Available at: <http://www.legislation.gov.uk/ukpga/2005/9/contents> (Accessed 20.11.12)
- Miller, H. (2010) "From 'rights-based' to 'rights-framed' approaches: a social constructionist view of human rights practice". *International journal of human rights*. Vol 14(6) pp 915-931
- Morgan, D.L. (1998) *Planning Focus Groups*. London: Sage
- Morgan, D. (1996) "Focus Groups" *Annual Review of Sociology*. Vol 22 pp129-152
- Morris, L. (2006) (Ed) *Rights: Sociological perspectives*. London: Routledge
- NHS Act (2006) "National Health Service Act 2006" Available at: http://www.legislation.gov.uk/ukpga/2006/41/pdfs/ukpga_20060041_en.pdf (Accessed 28.03.2015)
- NHS Constitution (2013) "The NHS Constitution" Available at https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/170656/NHS_Constitution.pdf (Accessed 26.06.15)
- NHS England Framework Agreement (2014) "Framework Agreement between the Department of Health and NHS England", Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/02/dh-nhse-framework-agreement.pdf> (Accessed 02.10.2014)
- NHS England (2014) "NHS England's Actions for End of Life Care: 2014-2016" Available at: <https://www.england.nhs.uk/wp-content/uploads/2014/11/actions-eolc.pdf> (Accessed 28.10.16)
- Nordgren, L. (2010) "Mostly empty words- what the discourse of "choice" in healthcare does". *Journal of Health Organisation and Management*. 24(2) pp109-26
- O' Byrne, D. (2012) "On the Sociology of Human Rights: Theorising the Language-structure of Rights". *Sociology* Vol 46 (5) pp829-843

O' Byrne (2003) *Human Rights: An Introduction*. UK: Pearson Education Ltd

O' Connor, D.J. (1967) *Aquinas and Natural Law*. London: McMillan

O' Neill, O. (1996) *Towards Justice and Virtue*. Cambridge: Cambridge University Press

Oregon DWDA (2013) "Death with Dignity Act" Available at:

<http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Pages/index.aspx> (Accessed 02.12.14)

Oxford English Dictionary (2015) "Euthanasia" [online] Available at:

<http://www.oxforddictionaries.com/definition/english/euthanasia> (accessed 24.06.15)

Pacheco, J. et al (2003) "A longitudinal study of attitudes towards PAS and euthanasia among patients with non-curable malignancy". *American Journal of Hospice and Palliative Care*. Vol 20 (2) pp99-104

Paltridge, B. (2006) *Discourse Analysis*. New York: Continuum

Parkes, C.M., Laungani, P., Young, B. (1997) (Eds) *Death and Bereavement Across Cultures*. London: Routledge

Patient (Assisted Dying) Bill (2003) Available at:

<http://www.publications.parliament.uk/pa/ld200203/ldbills/037/2003037.pdf> (Accessed 17.03.16)

Pausman, HRW., Rurup, ML., Willems, DL., Onwuteaka-Philipsen, BD. (2009) "Concepts of Unbearable Suffering in the context of ungranted requests for euthanasia: qualitative interviews with patients and physicians. *British Medical Journal* 339 p4362

Paust, J. (1995) "The human right to die with dignity: a policy oriented essay". *Human Rights Quarterly*. Vol 17(3) pp463-487

Pearlman, R. (2005) "Motivations for Physician Assisted Suicide." *Journal of General Internal Medicine*. Vol 20(3) pp234-239

Philips, N. Hardy, C. (2002) *Discourse Analysis; Investigating Processes of Social Construction*. California: Sage

Pierson, C. J. Randall Curtis D. L. Patrick (2010) "A good death: A qualitative study of patients with advanced AIDS" Published online: 27 May pp 587-598

Policy for Prosecutors (2010) "Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide". Available at:

http://www.cps.gov.uk/publications/prosecution/assisted_suicide_policy.html (Accessed 24.05.12)

Populus (2015) "Dignity in Dying Poll". Available at: <http://www.populus.co.uk/Poll/Dignity-in-Dying/> (Last accessed 28.04.16)

Pretty v United Kingdom - 2346/02 [2002] ECHR 427 (29 April 2002) Available at: file:///C:/Users/Sharon/Downloads/1679_Consejo-Europa_Case-Pretty-2002.pdf (Accessed 17.03.16)

Pretty v DPP [2001] UKHL 61 (29th November, 2001) Available at: <http://www.publications.parliament.uk/pa/ld200102/ldjudgmt/jd011129/pretty-1.htm> (Accessed 17.03.16)

Public Health England (PHE) (2013) "New report from PHE shows improvements in end of life care" (November, 2013) Available at: <https://www.gov.uk/government/news/new-report-from-phe-shows-improvements-in-end-of-life-care> (accessed 27.10.16)

Public Health Oregon (2014) "DWDA prescription recipients and deaths 1998-2013" Available at: <http://public.health.oregon.gov/ProviderPartnerResources/EvaluationResearch/DeathwithDignityAct/Documents/year16.pdf> (Accessed 02.12.14).

R (Nicklinson) v Ministry of Justice (2012) EWHC 2381 (Admin), (2012) MHLO77 Available at: <https://www.judiciary.gov.uk/judgments/tony-nicklinson-judgment-16082012/> (Accessed 17.03.16)

Rawls, J. (1971) *A Theory of Justice*. London: Bellknap Press of Harvard University

Richards, N. (2014) "The death of right-to-die campaigners". *Anthropology Today*. Vol 30(3) pp14-17

Richards, N. (2012) "The fight to die: older people and death activism". *International Journal of Ageing and Later Life*. Advance access

Rosen, M. (2012) *Dignity: Its History and meaning*. Cambridge: Harvard University Press

Royal College of General Practitioners (2014a) "Assisted dying" Available at: <http://www.rcgp.org.uk/policy/rcgp-policy-areas/assisted-dying.aspx> (Accessed 01.12.14)

- Royal College of Physicians (2014b) "RCP reaffirms position against assisted dying" Available at: <https://www.rcplondon.ac.uk/press-releases/rcp-reaffirms-position-against-assisted-dying> (Accessed 02.12.14)
- Scolding, N. (2011). "Right to die?" *Brain*, 134(1), pp.318-321.
- Scotland Act (1998) "Scotland Act 1998" Available at: http://www.legislation.gov.uk/ukpga/1998/46/pdfs/ukpga_19980046_en.pdf (Accessed 21.04.15)
- School of Advanced Study (2016) "BSA Sociology of Rights Study Group". Available at: <http://hrc.sas.ac.uk/networks/bsa-sociology-rights-study-group> (Accessed 16.12.16)
- Seale, C. (2010) "The role of doctors religious faith and ethnicity in taking ethically controversial decisions during end of life care". *Journal of Medical Ethics* Vol 36 pp677-682
- Seale, C. (2009) "Legislation of Euthanasia or Physician Assisted Suicide: A Survey of Doctors Attitudes". *Palliative Medicine*. Vol 23 pp205-212
- Seale, C. (2006) "Characteristics of end-of-life decisions: survey of UK medical practitioners" *Palliative medicine* Vol 20(7), pp.653-9
- Seale, C. (2004) (Ed) (2nd Ed) *Researching Society and Culture*. London: Sage
- Seale, C. (2000) "Changing Patterns of Death and Dying". *Social Science and Medicine*. Vol 51(6) pp917-930
- Seale, C. (1998) *Constructing Death*. UK: Cambridge University Press
- Seale, C., Judd, M. (2011) "Joining a right to die society: Motivation, beliefs and experiences". *Mortality: Promoting the interdisciplinary study of death and dying* Vol 16 (3) pp223-241
- Seale, C., Van der Geest, S. (2004) "Good and Bad Death". *Social Science and Medicine* Vol 58 (5) pp883-885
- Short, D. (2009) "Sociological and Anthropological Approaches" in Goodhart, M. (2016) (3rd Ed) *Politics and Practice*. Oxford: Oxford University Press pp93-109
- Simon Binner (2016) "How to Die: Simon' Choice". Available at: <http://www.bbc.co.uk/programmes/b070jm26> (Accessed 16.03.2016)
- Sjoberg, G., Gill, E. A., & Williams, N. (2001). "A Sociology of Human Rights". *Social Problems*, 48(1), pp11-47
- Smith, R. (2000) "A Good Death". *British Medical Journal*. Vol 320 pp129-30

- Smith, S., Schaffer, K. (2004) *Human Rights and Narrated Lives*. UK: Palgrave MacMillan
- Stammers, N. (2003) "Social Movements, Human Rights and the challenge to power". Proceedings from the American Society of International Law pp299-300
- Stammers, N. (1999) "Social Movements and the Social Construction of Human Rights". *Human Rights Quarterly*. Vol 21 (4) pp980-1008
- Stanford, P. (2011) "Why must I go on living like this?": "Locked in" stroke victim Tony Nicklinson has embarked on a landmark legal battle to win the right to die". *The Daily Telegraph*. London, 2nd December p35
- Steinhauser, K., Clipp, E., McNeilly, M., Christakis, N., McIntyre, L., Tulskey, J. (2000) "In Search of a Good Death: Observations of Patients, Families, and Providers" *Ann Int Med* 132 (10) pp825-832
- Stewart, D. Shamdasani, P. (1990) *Focus Groups: Theory and Practice*. London: Sage
- Suicide Act (1961) Available at: <http://www.legislation.gov.uk/ukpga/Eliz2/9-10/60>
- (Accessed 17.11.12)
- Thorns, A. (2010) Ethical and Legal Issues in End of Life Care. *Clinical Medicine* Vol 16(3) pp282-285
- Tonkiss, F. (2004) "Using Focus Groups" in Seale, C. (2004) (Ed) (2nd Ed) *Researching Society and Culture*. London: Sage pp194-206
- Torrance, H. (2012) "Triangulation, Respondent Validation and Democratic Participation in Mixed methods Research". *Journal of Mixed Methods Research*. Vol 6(2), pp.111-123
- Tosh, J. (2006) (3rd Ed) *The Pursuit of History*. UK: Pearson Longman
- Turner, B. (2nd Ed) (1996) *The Body and Society*. London: Sage
- Turner, B.S. with Samson, C. (1995) (2nd Ed) *Medical Power and Social Knowledge*. London: Sage
- Turner, B. (1993) "Outline of a Theory of Human Rights". *Sociology*. Vol 27 pp489-512
- Turner, B.S (1992) *Regulating bodies: Essays in medical sociology*. London: Routledge
- Universal Declaration of Human Rights (1948) Available at: <http://www.un.org/en/documents/udhr/index.shtml> (Accessed 25.04.12)
- Vincent, A. (2010) *The Politics of Human Rights*. Oxford: Oxford University Press

Voas, D., McAndrew, S. (2012) "Three Puzzles of Non-religion in Britain". *Journal of Contemporary Religion*. Vol 27(1) pp29-48

Voluntary Euthanasia (Legalisation) Bill (1936) Available at:

<http://hansard.millbanksystems.com/lords/1936/dec/01/voluntary-euthanasia-legalisation-bill-hl> (Accessed 17.03.16)

Waldron, J. (Ed) (1987) *Nonsense Upon Stilts. Bentham, Burke and Marx on the Rights of Man*. London: Methuen and Co

Walter, T., Murray-Parkes, M. (2015). *Personal communication*. CDAS conference, Bath 5th June.

Walter, T. (1994). *The revival of death*. Psychology Press.

Walter, T. (1991) "Modern Death: Taboo or not Taboo". *Sociology* Vol 25, (2) pp293-310

Warnock, M., McDonald, E. (2008) *Easeful Death: Is there a case for assisted dying?* Oxford: Oxford University Press

Waters, M. (1996) "Human Rights and the Universalisation of Interests: Towards a Social Constructionist Approach". *Sociology* Vol 30 pp593-600

Wicks, E. (2007) *Human Rights and Healthcare*. Oxford: Hart Publishing

Wilson, R.A. (2007) "Tyrannosaurus Lex: The Anthropology of Human Rights and Transnational Law" in Goodale, M. and Engle Merry, S. (Eds) (2007) *The Practice of Human Rights: Tracking Law between the Global and the Local*. Cambridge. Cambridge University Press pp342-366

Wilson, R.A. (2006) "Afterword to "Anthropology and Human Rights in A New Key"; The Social Life of Human Rights". *American Anthropologist* 108(1) pp77-83

World Federation of Right to Die Societies (2015) "Ensuring Choices for a Dignified Death" Available at: <http://www.worldrtd.net/> (Accessed 04.11.15)

Wyatt, J. (2009) *Matters of Life and Death*. UK: Inter-Varsity Press.

