Planning for Death?

An ethnographic study of choice and English end-of-life care

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Summary

In 2008 the National End of Life Care Strategy was released in England to create a large-scale change in the way dying patients were cared for. This dissertation explores the meaning, practice, and experiences of end-of-life care (EOLC). It is based on ethnographic fieldwork from 2010-2012 that follows policy into and across healthcare practice and the daily lives of those living with life-limiting conditions.

The first part of the study analyses the discourse of policy as evident in documents, policy events, and interviews with policy-makers, to understand the core values and motivations within this new field. By emphasising patient choice through advance care planning as a way to facilitate a 'good death', these polices have reshaped how persons, as dying patients, could be known and how they are positioned within the healthcare system as autonomous, reflective individuals.

Documents like the Preferred Priorities for Care are used to facilitate this process. As observed during clinical visits and expressed in interviews, healthcare professionals selectively use such forms, thereby demonstrating varying professional values, and treat their completion as a task. The layout and use of the forms influences professional-patient interaction and the 'choices' that can be made.

The second half of the dissertation focuses on the experiences of those who are the subject of EOLC policy and is based on long-term interaction with 10 people (up to 14 months), often in their own homes and involving their daily routines and family; this is supplemented by an additional 43 in-depth interviews and observations of support groups. Being embedded in a social web of relations was a prominent feature of our encounters.

Maintaining familial relationships and roles is important to people and they do this by navigating the flow of care and concern within the family. Assumptions about the linear trajectory of dying and the finitude of death are challenged by people's experiences of prolonged waiting and incomplete endings as they continued to be entangled in social relationships.

Consequently a wider notion of personhood beyond individual patienthood should be adopted for understanding living at the 'end of life'. Shifting the focus from choice as an individual act and object to one of interaction, I demonstrate how a relational approach to the study of end-of-life care challenges the emphasis on the dying individual and the dichotomy between care and choice. Overall, this ethnography demonstrates the difference between how policy conceptualises end of life and choice and the way people, who may be in this category, experience living with life-limiting conditions.

This dissertation is the result of my own work and includes nothing which is the outcome of work done in collaboration. No part of it has been submitted for any other qualification, and it does not exceed the word limit granted permission by the Degree Committee of the School of Clinical Medicine.

Acknowledgements

When I look back over the many days that went into this dissertation, I am astounded and incredibly thankful for all the people who have helped me reach this goal. On every single day, there has someone, often many people, who have encouraged or challenged me to see it through to the next. If I began to list them all individually, this section would be longer than the list of references at the back!

Firstly, I would like to acknowledge the dedication and support from my supervisors. Stephen Barclay has admirably tolerated my difficult questioning of the very policy and practice he is involved in. In equal measure, he has prompted me to question what practical application anthropological insights may bring and our meetings have frequently featured such debates. Simon Cohn has been a wonderful ally in a department that has often felt alien. His office library has always felt like a welcome refuge and our discussions and his probing, which often left me perplexed, has encouraged my ideas grow. I am grateful for both of their support, both known and unknown, and for providing me with the independence to pursue my own ambitions.

Secondly, this research would be incomplete without the generosity provided by those who have been part of it. From the clinicians that initially let me follow them around, to the long-term participants who welcomed me into their homes. In the following chapters, it will

become apparent how the time I spent with them vividly shaped what I re-count within these pages. Additionally, I would like to thank the National Institute for Health Research Collaboration for Leadership in Applied Health Research and Care for funding my doctoral studies, numerous conferences, and fieldwork, and the Primary Care Research Network for providing additional funds to remunerate clinical participants for their time spent in interviews.

Lastly, I am indebted to my family, friends, and colleagues who have been unwavering in their support and encouragement. Many have not always understood what (or why) I was studying but never let me doubt myself. Corridor conversations and care packages complete with tea and chocolate have helped me to see this through. In particular, I would like to thank Rachel Douglas-Jones and Julie Ellis for our catch-ups and their eagerness to read an entire draft of this tome. It is a special ability to be able to get someone out of their own head and help them make links beyond what is immediately apparent to them. And last, but definitely not least, my immeasurable thanks is due to Lukas who has had to tolerate my ramblings, odd interests, and working patterns. He has always managed to pick me up when I fell down. And here I am, standing proud.

Erica Borgstrom 20.08.2013

I would like to additionally thank my examiners, Prof Martin Richards and Prof Myra Bluebond-Langner for their helpful comments and engaging discussion. -23.05.2014

Early on in my fieldwork I visited Mable in the hospital. As she held my hand, I realised I was doing more than just research. I am incredibly thankful to all of those who have let me into their lives.

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Several images have been purposely blurred for the online version of this document.

Wrestling with end-of-life care choice

Extracted notes from my research diary – early 2010

A professor once told me that anthropology is about serendipity and grasping opportunities. I often feel like I fell into studying English end-of-life care and in that tumble I lunged at exploring 'choice'. The word stood out like a beacon, flashing its shiny face at regular intervals as if it were the saving grace. It felt so polemic and its "good fit" with health policy just didn't sit right with me.

Prior to my encounter with these polices and their rhetoric, I had never thought of death being a choice, even when suicide was concerned. We die because we live, and the timing of that death is more than just a single swift decision but a jumble of emotion, experiences, and tensions that roll up and down the hills until they reach their final resting place. The deaths I had experienced of family and friends were either sudden – bomb blasts and heart attacks – or drawn out as they dwindled under diseases. Choice, in particular individual choice of the dying person, seemed like a foreign concept in light of these events. Part of my interest in end-of-life care choice is therefore to understand how it can be present in a room that has shut it out.

In contrast, my previous research interests on maternal health in Africa highlighted how choice – especially choice in terms of place of birth that mirrors the prime choice touted in end-of-life care about place of death – was rarely as autonomous as the concept implied. Where a child was born was as much more a combined result of the access to healthcare, familial relationships, belief in the health system, and ability to physically move the woman's body to the clinic as it was her expressed desire to be

there. Moreover, when speaking to women about where they had given birth, similar reasons validating the appropriateness of the clinic and home were used for both scenarios: safety, what was morally right, it was what they were advised to do. Place was as malleable as choice.

If place is flexible with similar places holding similar values, and choice is constrained and yet valiant, what is the value of looking at end-of-life care choice that focuses on place of death? The options available seem to be one's own home, hospital or hospice. But many people die outside of these places, for example on the streets; and from a global perspective, the comfort and technology implied in those images of home and hospice are lacking. I often joke with my partner that if I were to know that I was dying now and was asked about "my choice", I would state that I want to die in Africa with the flies on me like so many others do. As we lay in bed, his mother's horror and my parent's reluctance dance in the shadows of the ceiling. Friends would probably disown me and doctors would refuse to let me fly. Would I be able to die, or even say where I want to die, 'knowing' this? Our anticipated reaction of my family, friends and healthcare professionals in charge of my care highlight how choice and one's death are not as individual and isolated as they appear at first glance.
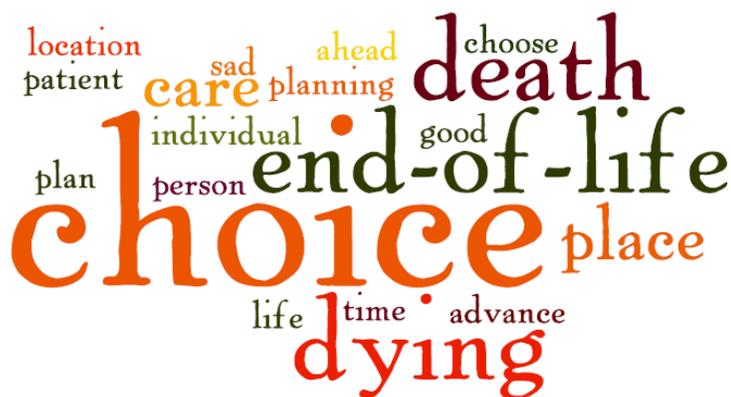
Image 1: Word cloud of End-of-Life Care Choice

Part 1: The Study

Chapter 1: Introduction – Locating an anthropology of English End-of-Life Care

1.1: Introduction

It is the autumn of 2009 and in an English stately home speaker after speaker at the regional end-of-life care conference tells the captivated audience how the "new pathway" and focusing on "patient choice" will change dying for the better. The current event is to promote an array of service re-developments to "deliver choice" at the end of life. The platform for these statements was set by revolutionary National End-of-Life Care Strategy for England launched in 2008, which has spurred great change in the way care is delivered to the dying, primarily through the National Health Service (NHS) and social care. Rather than "neglecting dying", it is to be actively managed – the event of death can be transformed by attending to the process of dying. Sitting there about to embark on my PhD on English end-of-life care (EOLC), I am left perplexed, as the previous fieldwork diary excerpt indicates, by how assured policy makers are that dying can be "good" and be made better through 'choice'. As McNamara (2004) noted, death can present a lack or limit of choice. Yet, policy statements embody core neoliberal values of choice, autonomy, and control and reject romantic ideas of death's fatalism. By focusing on a history of palliative care, English end-of-life care choice discourses carefully circumvent assisted-dying debates and draw the audience's attention to the experience of dying over time; accordingly, I focus

on how 'choice' is mobilised within this context that presented dying as a process and excludes discussions of assisted-dying and euthanasia. Choice, as the conferences speakers talked about it, is about planning for the future and anticipating the individual's death rather than determining when death should occur. These discussions remain pertinent in 2013, at the time of writing, as the popular press interrogate allegations of clinical negligence and a lack of compassionate care around dying.[1] At the heart of these concerns is an interest in how dying people are treated and the role of patient choice towards the 'end of life' – these are the very issues the National End-of-Life Care strategy sought to tackle. This dissertation explores what 'choice' is in relation to English end-of-life care and how people who are confronted with the issues that long-term and/or terminal illnesses raise experience these. I focus on how these issues create, shape, and are influenced by relations and understandings of personhood. In doing so, I demonstrate how the ideals of policy are (or not) translated into practice and do not always resonate with people's daily experiences of life, explaining to some extent how five years after the introduction of the strategy these 'scandals' continue to capture the public's imagination.

 In order to understand end-of-life care on its own terms, I have adopted an ethnographic approach that is inherently broad to look firstly at healthcare policy, then healthcare practice, and lastly the daily experiences of people who are the subject of such policy and practice. The format of this dissertation roughly follows this tripartite approach. Drawing on anthropological methods and theories, this sets end-of-life care and 'choice' against a broad, cultural context locating it in the intersections and dialectics between persons and

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[1] This is highlighted by two large news stories. "The Mid-Staffordshire scandal" involved a high number of deaths attributed to deficient care within a specific hospital trust. "The Liverpool Care Pathway debacle" centred around stories of people who may not have died had the clinical tool not been applied to their care, which involved the withdrawal of fluids alleging in some cases physician-assisted dying which is illegal in England.

structures. The various chapters of this dissertation outline what the category of 'end of life' means, and how people experience this phase and what 'choice' and 'care' are and how they are done. Drawing on observations and in-depth interviews, the examples often read as stories into people's lives. They are more than just accounts of what was seen and heard; they are tales of relationships that permeate throughout this study.

There are different scales and kinds of relationality addressed in this interpretation of English end-of-life. When examining healthcare policy, I highlight how discourses of death and choice and the categories within end of life shape the way healthcare is envisioned and practiced, including how it constructs patients as subjective dying individuals. Such persons are encouraged to do "advance care planning" and document their choice, particularly their preferences for where they would like to die; I describe the act of documenting choice and the material objects used to do this. In this way, such forms are not neutral holders of patient choice, as envisioned by policy and health practitioners, but active agents in how end-of-life care choice is known and mobilised within the health system. Drawing on from this, I explore how choice is shaping the way healthcare professionals relate to themselves and their patients as they practice 'care'. These activities, which focus on the individual, sharply contrast with how people interact in their daily lives as part of caring networks and relationships within their families. By illustrating how people relate to themselves and others through care and the experiences they have towards the end of life, I open up the notion of personhood. This social personhood contrasts with personhood based on individual choice that is engendered in end-of-life care policy. A focus on relationality therefore shifts the very subject that lies at the heart of this study and this is done by examining how personhood is ascribed and acted upon.

This present chapter provides a background to the theoretical approach adopted for this interpretation as well as outlining in more detail the National End-of-Life Care strategy that prompted the research. Ultimately, this study illustrates how the images of dying portrayed in English end-of-life care do not always match how people practice choice or experience this period. This is because policy is idealistic and focuses on individual choice as a way to manage a linear dying process. Both of these are cultural constructs and do not capture the complex web of relationships and experiences that living and dying represent. Rather than focus on the individual and dying, I suggest an approach that foregrounds the meaningful relationships people are part of and the day-to-day experiences that make up living to understand what life, and therefore, end of life is about.

1.2: Anthropological Orientations

Anthropology is the study of people that seeks to understand what people do, how people interact with one another, and what they think about what they do (Bernard 2011). It often involves studying a group of people the researcher is not part of – traditionally another cultural group but it can include studying social groups within one's own culture – as a way to interrogate the language and practices within which people live and understand their lives. Through this, anthropological studies disrupt "common sense and make us re-examine our taken-for-granted assumptions" (Marcus and Fischer 1986:1). As Beattie notes, "one way of understanding things is to explain them" (1959:148) and anthropologists do this through ethnography where descriptions are met with disentanglements of meanings, ideologies, constructions and activities (Kessing 1987; de Meer *et al.* 1993). In particular, medical anthropology has been concerned with patient experiences (e.g. Kleinman 1980) and the analysis of biomedical knowledge and practices (e.g. Lock 2001). There has also been an increased interest in power relations since Marx (1977) and Foucault (1977),

although anthropologists have frequently been interested in social relations as a way of understanding culture (Strathern 2005). Here I outline three key anthropological concerns that are present throughout this dissertation: the use and meaning of categories; relations, interaction, and relationality; and the notion of subjects and personhood. The matters addressed in this study speak to the current trend in anthropology to address national and international issues (e.g. Ong and Collier 2005), concerns about biopolitics (e.g. Krause and de Zordo 2012), the relationship between governments and persons (e.g. Shore and Wright 1997), local manifestations of neoliberalism (see Gershon 2011), as well as relations and detachment (e.g. Candea 2010). Additionally, I specifically outline key issues within medical anthropology and how this research can be located within this disciplinary sub-field. As Knauft declares, anthropologists are "like bricoleurs [who] combine pieces of different perspectives …in relation to particular projects and topics" (2006:407) and the approach I have adopted for this dissertation reflects a nature of applying various theories to different topics of choice and end-of-life care rather than adopt a single grand theory.

Anthropology has a long history of looking at cultural categories as a way of understanding other societies (e.g. Levi-Strauss 1958). Classification systems provide an insight into how people envision the social world and the things within it (Douglas 1966), including how they distinguish good from bad. Whilst an interest in classification and categories was part of documenting variations in kinship terminology (see Morgan 1870), contemporary anthropologists are interested in how categories are defined to explore how people construct knowledge and what they know (see Kaufman 2000). Similarly, discourse analysis and exploring rhetoric can examine how categories function, what they enable and what they exclude (Carrithers 2005). Deconstructions of discourse can trace where concepts

come from, the relational and material consequences they have, and how language and practices are used to moderate the behaviour of others and the self (Foucault 1976). Whilst I engage with these ideas throughout the dissertation, in Chapter 3 and Chapter 4 I use these ideas to understand what end of life and choice mean in contemporary England. Anthropologists also utilise abstract categories as a way to analytically express what they observe, and in Chapter 3 I discuss how concepts developed in social theory have migrated into healthcare policy through the process of sociolization as described by Barbour (2011).

As noted above, anthropologists are interested in relationships and Candea (2009) has identified three ways in which the discipline engages with relationality: ethnographically, analytically, and through its view on engagement with research participants. In the first instance, anthropologists are interested in the relations between different entities (using Latour's notion of relation; Latour and Woolgar 1979) and anthropological theory is often about social relations (Gell 1998). For example, medical anthropologists have shown how new approaches to intervening in life processes, such as death, has altered the relations between patients, medical professionals, and health authorities as well as the "relations between bodies, markets, and the state" (Franklin and Lock 2003:64). Relations are therefore often the subject matter of anthropological studies and I have taken relationality in terms of looking at relations between people, objects, and concepts to be a unifying theme of this dissertation. It is about and through relations that choice in the context of English end-of-life care is discussed in the following chapters.

Secondly, anthropologists use the notion of relationality to make sense of their data analytically. Interpretations are based on connections (Dilley 1999) and this is where the concept of context comes to the fore in anthropology. By placing the subject matter within

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a larger cultural context, anthropologists seek to demonstrate how people know the world around them and themselves through relationships (Strathern 2005) and that "things enter the world of human experiences…through their inter-relations" (Rapport 1999:192). This does not mean that all relations can be captured within any one study; instead, there is a focus on the relations that are engaged in interaction. Indeed, there has been a recent move within anthropology to look at the limit of relationality, focusing less on when relationships are present and explore when disconnection or detachment is possible, the ability of relations to remain and the intensity of relations (see Candea 2010). I build on this work in the later chapters where death poses the possibility of breaking relationships. I also turn this reflexively onto the research endeavour, as through ethnography, the researcher is engaged in relationships with participants. It is through such engagements that anthropologists begin to see the world as others do, but it also a way of ethically relating to other persons. What it means to be related to others is therefore a concern for anthropology, not only in making sense of what one studies but also in how this affects the research process and those involved in it.

This connects to the last topic of subject-making and personhood, which I use to illustrate the anthropological concern about what it means to be a person. This is relevant to this study not only in how different ideas of personhood and relatedness affect the way bodies and experiences are known (Strathern and Stewart 1998) but also in drawing attention to the particular discourse around the 'individual' used in English end-of-life care policy. Foucault (1977) has highlighted how the modern concept of the individual is a historical construct, whilst Morris (1994) claims that such conceptions are cultural categories, and others have noted that the concept of the individual can exist alongside other notions of

persons that rarefy independence and autonomy less (Pool and Geissler 2005). Instead of

using the term 'individual', anthropologists tend to use the term 'person' as this implies

social relations (Strathern 2005) due to its linguistic link to the Latin word for mask and

hence performance (Carrithers 1985). By being interested in persons, anthropologists seek

to understand the process of becoming (e.g. Carsten 1995; Lambeck and Strathern 1998;

Franklin and Lock 2003) and thus the practices and relationships that make human beings

culturally distinct from other aspects of their social world. It is different from selfhood,

which focuses on the creation of distinct identities, but similar to subject-making more

generally, in that descriptions of personhood outline the culturally informed qualities of

what is considered to be a 'person'. Kaufman and Morgan note that "anthropologists have

often used the margins of life as a site for examining the making and unmaking of persons

and relationships" (2005:318) and I build on this tradition of exploring personhood and

subject-making by demonstrating how appealing to different notions of individual and

person lead to different ways of framing relationships between people and between people

and concepts or objects. Moreover, I describe how people conceive of themselves in terms

of relationships and that it is through these relationships that they become known.

   Lastly, medical anthropology is a sub-field of anthropology that builds on the theories and

methods within the discipline to understand medicine, health and illness within different

cultural contexts. A fundamental aspect of this approach is that "health-related issues…are

far more than narrow biological phenomenon" (Singer and Baer 2012:1). One element

medical anthropology draws on biological anthropology to understand the inter-relationship

between 'culture'/'society' and 'nature' (e.g. McElroy and Townsend 1996) and is similar to

social medicine (McKeown and Lowe 1966). Other medical anthropologists are more akin to

social/cultural anthropology in that their work engages with wider debates about meaning-making and theorising about ways of being (e.g. Kleinman 1978; Frankenburg 1980; Fardon *et al.* 2012). This research is informed and inspired by the latter.

Early medical anthropologists were interested in individual illness experiences, practices of healing, and the social meaning-making or construction that is involved in creating, sustaining, and understanding health (e.g. Kleinman 1988; Good 1994). For example, this work sought to explain how people from different cultures could experience illness differently (e.g. Kleinman 1980; Poss and Jezewski 2002; Kreling *et al.* 2010 consider hospice care) and to describe culture-bound syndromes (e.g. Simons and Hughes 1985). Research into these areas can generate more culturally-sensitive health interventions that respond to local logics of well-being (e.g. Bilu and Witztum 1995). More contemporary examples of this approach that focus on experience and the symbolic can be found in Moerman's discussion of the placebo effect (2002) and cross-cultural studies of new medical technologies that focus on personal experiences and interpretations of disease and illness (e.g. Inhorn and van Balen 2002).[2] This dissertation draws on this approach in that I engage with people's experiences of health and illness and through an exploration of how relationships and social constructions shape these experiences.

Another element of medical anthropology – known as critical medical anthropology – focuses more on the macro processes and structures of healthcare, focusing particularly on structural and global health inequality. This approach is influenced by Marxian and/or Foucauldian ideas and seeks to outline issues of power that affect the distribution and construction of health, disease and illness, and can include issues of identity politics (e.g.

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[2] Inhorn (2007) is similar but also draws on aspects more typical of critical medical anthropology, thereby illustrating the possible overlap between approaches within medical anthropology.

Singer 1994), structural violence (e.g. Quesada *et al.* 2011) and biological citizenship (e.g.

Petryna 2004). Farmer (1999) and Scheper-Hughes (1993) have used an anthropological

approach to locate disease and death within wider global changes and debates to highlight

the possibilities for change. Another shift has been to focus on biomedicine and new

medical technologies, examining them in terms of the disciplining techniques they exert

over people's bodies and how understandings of the body change (Lindenbaum and Lock

1993). Whilst the research presented in this dissertation looks at how policy shapes

relations, and is influenced by discussions of power and biomedicine, I do not discuss wider

issues of inequality or actively seek to engage in applying such approaches to changing the

way end-of-life care is practiced. Instead, the purpose of this research is to describe the

social context of choice and end-of-life care, how they are practiced and experienced.

Therefore, it engages with discussions of bio-politics and the role of biomedicine in people's

lives, in particular through the construction of patienthood, whilst also highlighting how

people experience personhood as distinct from this.

  Anthropology seeks to understand the social world people live in. Bringing an

anthropological approach to the study of English end-of-life care provides a methodological

and theoretical framework for understanding meaning, structures, and practices that

influence the way 'end of life' is experienced. It allows for the unpacking of policy discourse

in order to examine how language and practices shape the way healthcare is delivered and

how people make sense of death and dying. Grounded in relationality, this approach allows

for particular attention to be paid to the interaction between factors – such as between

policy and practice and between people – rather than view them in isolation. Such

descriptions allow for discussions of how and why things are the way they are. Additionally,

by focusing on relationships, this study unpicks the meaning and practice of care in the context of end of life by exploring how choice is done in clinical settings and how people sustain their personhood through relationships. This approach therefore differs from many studies into English end-of-life care that focus primarily on the reporting on improving practices and/or choice[3] by contextualising these wider issues with what it is like to experience end of life based on policy frameworks.

1.3: Studying Dying

The study of end-of-life care, as it deals with dying persons and managing death, falls under the wider umbrella of dying studies, which has grown since the 1960s, and includes exploring what death is, how dying occurs, and how death and bereavement are experienced and practiced. Within this interdisciplinary field there are many different approaches to the study of death, and this section provides an overview of the main areas and their contributions. In particular, I focus on the kinds of death that are often discussed within the literature, namely biological/physical death, social death, and good death. Whilst dying studies is an academic pursuit in its own right, the outcomes of such research has had implications for the way death is viewed within society and how the care of the dying is carried out, which is discussed further in Chapter 3. Overall, the scope of dying studies illustrates the diverse ways death and dying have been understood and the ability for these studies to shape the way the process, occurrence, and meaning of death are understood.

1.3.1: Main Areas of Dying Studies

For the purposes of this overview, I identify five main categories of dying studies. Whilst I outline them as independent bodies of literature, there is considerable overlap within and between them and as death, dying and bereavement continue to change and be examined

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[3] For example: Seymour *et al.* 2010; O'Brien and Jack 2010; Gardiner *et al.* 2012; Harrision *et al.* 2012.

from more disciplinary perspectives. Therefore, this summary is inherently limited. Whilst

dying research is diverse in its geographical focus, for the purposes of this review the main

focus is on 'Western' societies due to shared cultural context, to some extent, with England

where this study is based.[4] The themes in dying studies include: 1) changing patterns and

discourses of death; 2) how dying is constructed or organised including ritual practices; 3)

how dying changes relationships and notions of the self; 4) ethical issues surrounding

controlling and timing death; and 5) practical aspects of improving the care of the dying.

Firstly, changing patterns and discourses of death include historical comparisons, studies

of the socio-demography of death, research on new practices around death, as well as how

death is discussed in popular media. An example of historical overviews and comparisons

include Aries (1981), Illich (1976) and Kellehear (2007), which trace the changing social

responses to death as societies have become more industrialised, urban and secular (Walter

1997). The overall argument is that as societies become modern, death becomes

increasingly private and treated within the medical sphere. From a demographic

perspective, changing patterns in death include an increase in deaths from chronic rather

than acute illness, deaths later in life leading to an aging population, and more deaths in

hospital settings (Howarth 2007).[5] Together these analyses have supported the notion that

death is a taboo within modern society, in that it is sequestered and not spoken about

(Mellor and Shilling 1993; Lee 2008).

In contrast to this, there has been an increasing interest about death and dying (as well as

overall health decline) in popular media. Walter (1994) states that there has been a revival

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[4] These include studies from America, Europe and Australia that tend to share religious histories, linguistic similarities, and neoliberal governments.

[5] Although there is considerable variation in the place of death both within and between countries – see Gomes *et al.* 2011; Thonnes and Jakoby 2013.

of death recently, bringing death into the public domain, which has coincided with the rise

of individualism. Such stories tend to focus on sudden death, the survivor narratives of

cancer, and the increased focus on awareness of dying. Seale (1998) refers to these as the

various dying scripts that are available to people to talk about, and do, dying. Together with

studies that show how death and dying is organised with institutions (see Sudnow 1967;

Glaser and Strauss 1968; Kaufman 2005), this area of dying studies focuses on the way dying

is structured. Rather than positing death and dying as stable biological processes, this body

of research illustrates the culturally informed and constructed ways in which death is

understood and practiced.

  A third area of dying studies focuses on how dying changes notions of the self and

relationships. For example, Kübler-Ross's (1969) work on the dying process framed the time

up-to death as a journey of self-growth and grief. Death is often represented as a crisis and

rupture in an individual's and social life (e.g. the account of dying scripts in Seale 1998; Ellis

2013 for a critique of the emphasis on rupture/crises), with practices required leading up to

and after death to enable restitution. In this way, much of the literature on mortuary rituals

focuses on how people use symbols and religion to create meaning from death, to facilitate

a time of crisis, and to re-order a person's role in society (Bloch and Parry 1982; Murray

Parkes *et al*. 1997).   By positing death as a time of transformation, these studies have

(re)created a sense that death is something that has to be 'worked through'.

  Fourthly, making sense of death – and the position of death and dying within the social

order – is also often at the heart of ethical debates about the timing and control of death.

These debates can happen within numerous forums, most notably within philosophy (e.g

Prado 2008) and palliative care (e.g. Randall and Downie 2010), although some texts are

aimed more at a popular rather an academic audience (e.g. Humphry 2005). The key

elements to these discussions are whether people should have some sort of control over

dying in terms of ending their own lives, whether this control should be exerted by the

person themselves or others, and if societies were to allow this kind of relationship to

death, what safeguards would need to be in place to separate dying through assisted suicide

and euthanasia from murder and genocide (see Tulloch 2007 or Jackson and Keown 2012

for overviews). Through these discussions, there is a sense that certain kinds of death and

dying are more socially acceptable than others due to the wider social understandings of

the body and personhood.

The last area of death studies, to be discussed, addresses end-of-life care and the practical

aspects of caring for the dying. The focus of these studies, often written about in the

medical and nursing literature, is the patient and professional experience of dying. Examples

of these include Wilkinson *et al.*'s (1999) study on patient and carer satisfaction of palliative

care services, surveys of patient preferences (Thomas *et al.* 2008), and the stress

experienced by nurses caring for the dying (Keidel 2002). What distinguishes this research

from the other types outlined above is the explicit purpose of improving care services. The

presence of this literature supports Walter's (1994) claim that death has become more of a

focus in modern society and observations that it is viewed within a medical remit (Kellehear

2009).

Overall, whilst I have separated the diverse dying studies literature into five key areas,

there is considerable overlap between the categories. The main purpose of this overview is

to illustrate the breadth of the field, its interdisciplinary nature, and how the focus of

particular studies can shape the main findings and discussions found within them. As a

collection, it seeks to understand what death is, how people experience dying, and what people do in response to death, dying and bereavement. For the purposes of my research, I am most interested in the ways death and dying are understood, and how practices and discourses shape the experiences of dying, instead of debating the ethical nature or the appropriateness of different practical treatments.

1.3.2: Definitions of Death

Earlier I noted that there has been a change in views and practices of death over time, and indeed, there are differences across space as well (Howarth 2011). Here I wish to focus on the various definitions that have been applied to death, primarily within the academic literature, to differentiate between the practices that surround the dying person and their body. Death can be defined as the final or permanent cessation of vital functions in an organism or the event that terminates life (OED 1996; Bernat 1998). However, it can also be understood as socially constructed and relevant to ideas about the person rather than just the physical being (Seale 1998; Green 2008). Exploring different definitions of death demonstrates how something considered inevitable and universal is nonetheless embedded in and imbued with social values.

Within biomedicine, death is marked by an absence of certain features considered vital for physiologically living. Previously, this was a pulse and the ability to breathe (Knudsen 2009). Technological changes in clinical interventions are now able to occasionally reverse these conditions, through resuscitation, rendering them inadequate for defining the permanence of death (Englehardt 1999; Pernick 1999). Today, brain death is understood as "the absence of cerebral responsiveness" (Knudsen 2009:29) and serves as the primary definition used within hospitals, particularly as a criterion for organ donation (Bruno *et al.* 2009).

Definitions of brain death illustrate what is seen important in the human body – the

rational mind located within the brain – and the ideal role of a person in society – to be a

conscious, able and autonomous individual (Lock 2002). Furthermore, how death is defined

has implications for what can happen after death; in the case of brain death, this allows for

organ donation as not all organs have 'died' and can therefore be transplanted into other

living bodies. Prior to declaring brain death, a patient may still be eligible for life saving

treatment. Defining death in such biological terms reduces physical presence to materiality,

and yet the meaning of these materials, such as the brain, has social implications in that

bodies are connected to persons and persons are interacting with bodies.

Alongside notions of physiological death, there is the category of social death, which may

not coincide with physiological death. Originally designed to talk about how patients

deemed to be close to death were treated as if they were already corpses (Sudnow 1967), it

is often used to discuss the disengagement of the dying person from and by the people

around him/her (Kellehear 2009), no longer fulfilling their social role or engaging in

everyday activities. Attending to social death is a way to counter overly (bio)medical

representations of death by locating the person within cultural practices and society (e.g.

Sweeting and Gilhooly 1997). In other cultures, physically living members of society may be

considered dead and therefore interacted with differently after particular rituals that signify

a transition into ancesterhood are performed (see Bloch and Parry 1982; Metcalf 1997; Lock

2002). For instance, among the Hadza, people who can no longer walk are left to recover or

die on their own (Woodburn 1982) and among the Mbuti, an ill person may be considered

'dead' as they are unable to hunt or gather, but only the 'dead dead' are mourned (Turnbull

1961). In Western societies, the mismatch in timing between social and physical death can

result in perceptions that the death was "too soon" or that the person "lingered too long" (Lawton 2000), reflecting ideals of what death should be: the passing of both body and person.

This relates to notions of 'good death'.[6] Contemporary interpretations of good death are historically linked to euthanasia and ideas of 'dying beautifully' with one's personal affairs in order (Kellehear 2007a). Definitions can include: notions of control, comfort, closure, dignity, awareness of impending death, and the presence of family. What has constituted a good death has changed over time. Today, within Western societies, it is accepted that deaths may be highly individualised to reflect personal perspectives and experiences (Kehl 2006). Nonetheless, most people attempt to achieve a death reflecting wider social values and scripts (Seale 1998; Masson 2002), and medical staff strive to provide deaths that conform with these notions, or at least a 'good enough death' (McNamara 2004). Behaviour and interactions are therefore adapted and modelled to fit this pattern of good dying. Patients who do not attempt to achieve a good death may be labelled 'bad patients' or as being in denial (Kelly and May 1982; Hart *et al.* 1998). Therefore, although it is accepted that the qualities of one's death may be personalised to reflect a neoliberal society, dying is a moral imperative and one's death – or how it is viewed – has implications beyond the individual.

The definitions of physical and social death represent death as being the absence of one thing or another, which are considered vital elements of what it means to be alive, to be considered a person within society. Although often discussed as separate (Kellehear 2008), Kalish (1968) illustrates how different concepts and perceptions of death are dynamic and

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[6] I have placed the term in single quotation marks as it is highly contentious and variable as well as readily used in English end-of-life care policy without referring to this diverse history.

co-exist. How death is classified has an implication for how someone is interacted with or what their position in society is viewed as. The definitions vary over time and space, reflecting cultural concerns and values. Similarly, what constitutes a good death has varied. However, rather than focusing on the loss of material or social attributes that may define a person, descriptions of good death embody morally and socially approved values in the form of behaviours, actions, or sequences of events. In this way, not only is death open to cultural construction but the dying process is as well.

Although these different categories of death have arisen through technical and academic discourses since the 1960s, these terms have taken on a life of their own within English healthcare policy and practice, as developed in the next section and Chapter 3. The shifting nature of understanding death, challenges the usefulness of these distinctions, particularly as they are taken up and changed through healthcare practice. In Chapter 6, I explore the relevance of 'social death' for explaining the way 'end of life' is experienced by those involved in this research. Overall, this discussion leads me to question to what extent 'end of life' is about death and dying, and how research into end-of-life care can be positioned within the wider debates within dying studies.

1.4: End-of-Life Care Strategy

This research was inspired by the End-of-Life Care Strategy (EOLCS) released by the Department of Health (DH) for England and Wales in July 2008 (DH 2008). In this section, I outline a brief history of the EOLCS and why it was formed. It draws on a strong history of palliative care within the United Kingdom, often claimed the home of the modern hospice movement (James and Field 1992).The policy was viewed as a key game-changer for the delivery of care for the dying within England – as the first of its kind to directly address the

care of the dying within the state-funded 'cradle to grave' service of the National Health Service (NHS)[7] – and is part of an international movement to improve the quality of death through advance care planning (EIU 2010). On a local level, commissioners of health services use the national healthcare policy as a standard for determining the level and kind of health services that are required. This results in many changes to the kinds of and scope of palliative and end-of-life care provided. The strategy is therefore not only a document but an agent of change and this idea of how policy influences healthcare practice through discourse and shaping categories is explored further in Part 2.

The DH is responsible for policy setting for the NHS, providing guidelines to improve care.[8] In the context of the EOLC, the strategy was the first of its kind both nationally and internationally and sought to provide a long-term vision for the care of the dying. The term strategy refers both to the document and to the polices set out in the 2008 document, which outlined ways to improve the care of the dying by focusing on 'end of life' and reforming services to be better "co-ordinated" and "patient-centred". Previous health strategies have focused on reducing mortality or morbidity or care of particular disease categories; the EOLCS focuses instead on a group of patients whose joining feature is their nearness to death, as identified and treated by medical professionals. The emphasis on this patient group and the quality of care they receive is seen to be finally addressing the "time bomb of the ageing population", as it has been called in policy meetings like the one I opened this chapter with, as the rate of death is set to increase within England from 2012.

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[7] The NHS was established in 1948 and is funded through taxation. Private health insurance is available but the NHS provides most treatment. More detail about the NHS can be found in Section 2.2.
[8] Due to devolution, other parts of the United Kingdom have powers to write and implement their own health policies and Scotland released a similar end-of-life care policy a few months later.

Prior to the strategy, there was no single policy for handling death and dying within the NHS despite its promotion as a 'cradle to grave' service. Most guidelines concerning death were disease-focused (e.g. DH 2001 & NICE 2004 concerning cancer) or about death certificates and post-mortems (e.g. DH 2003b). The main remit of what is now considered EOLC was provided primarily as palliative care and by hospices.[9] Their provision was patchy reflecting the historical and local variation in the development of such services, especially as the primary funding for hospices was charitable. Where such services were available, access was inequitable and often restricted to cancer patients (Murray 2008). Moreover, media reports featured incidents of poor practice more generally within the NHS where dying patients were not treated with respect and dignity; such deaths frequently occurred within hospital settings that did not align with people's preferences (e.g. NatCen 2009). The EOLCS was therefore designed to address these concerns.

The strategy was developed over a year by policy makers and palliative care specialists, building on the recommendations made by the NHS End-of-Life Care Programme established in 2004. This programme sought to roll-out tools such as the Preferred Priorities of Care (PPC), Gold Standards Framework (GSF), and Liverpool Care Pathway (LCP), which emphasise patient preference and co-ordinated care; these are further promoted in the EOLCS. Ultimately, the implementation of the national strategy would "enhance choice, quality, equality and value for money" (DH 2008:33) and allow people to have "good deaths" as outlined within the document.

The backbone of the strategy is the EOLC pathway, discussed in more detail in Chapter 3. It posits that once patients are identified as possibly being in their last year of life, their care

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[9] See Glossary (Appendix 1) for a definition of these terms. A deconstruction of some of these terms is in Chapter 3.

and wishes leading up to their death should be anticipated, discussed and documented.

Policy makers stressed that patients should have a choice about where they die.

Additionally, since such patients are likely to be treated under multiple arms of the NHS,

their care is to be co-ordinated through the sharing of patient notes, especially of

documents that outline their preferences for care and advance refusals of treatment. Such

co-ordination is envisioned to improve the likelihood that patients can die at home, if they

choose to. This process is known as advance care planning (ACP) and is posited within the

EOLCS as the key way to improve the care of the dying and increase the rate of home

deaths. The EOLCS additionally outlined ways to improve the visibility of dying in British

healthcare and society, and sought to "change attitudes to death and dying in society" (DOH

2008:11) by launching a social media campaign known as Dying Matters.[10] Through changes

on a national, societal, service and individual level, care of the dying was to improve under

the policies of the EOLCS.

  Since 2008 there has been increased funding for EOLC within England, even when other

services within the NHS had to make efficiencies (NEOLCP 2008). The primary focus of

funding has been in implementing the use of tools identified as 'best practice', such as the

Preferred Priorities of Care Document (PPC – further discussed in Chapters 4 & 5), and

training generalist and specialist staff in communication skills and end-of-life care, such as

symptom management. On a local level, health trusts have invested in evaluating their

service provision and improving services to provide more EOLC across the region and out-of-

hours. Nonetheless, media reports of poor care and controversy surrounding EOLC tools like

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[10] Dying Matters seeks to change public attitudes and knowledge about death, dying and bereavement by encouraging more open communication. See: http://dyingmatters.org/

the Liverpool Care Pathway[11] and assisted-dying[12] continue to outweigh the media coverage generated by the Dying Matters campaign. Moreover, the Coalition government elected in 2010 set out to reform the NHS in 2013, by localising services thereby challenging the ability to realise more uniform care across the nation.

End-of-life care is therefore an evolving subject within England as services continue to change. The key components of the EOLCS are: identifying and talking about dying, patient choice and advance care planning, and increasing the rates of home death. To operationalize these goals, health and social care professionals were to be trained in end-of-life care and communication, and services were to be re-designed around enabling more home care, care planning, and care in the last days of life. Although the policy is about death and dying, the approach is wider and encompasses aspects of care, structural arrangements within the NHS, and what English society should be like. By drawing on narratives of accountability, quality, and 'value of money', EOLC is part of broader cultural shifts in how healthcare and daily living are presented. In this way, the EOLCS provides insight into cultural dimensions that are larger than just understanding an English way to approaching death.

1.5: Choice and Care

When discussing current healthcare practices, since Mol's *The Logic of Care* (2008) it is imperative to address the conceptual centrality of the relationship between choice and care. Her work draws on a larger body of literature and research that comments on the role

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[11] The LCP is a recommended tool for best practice in EOLC in national policy. Originally modelled on hospice care to minimise extensive treatment when a person is dying in hospital; itt was regularly used in other clinical settings as well. Following extensive negative media coverage in late 2012, an independent review recommended it be phased out (see Neuberger *et al.* 2013).

[12] During the course of this study several high-profile cases for assisted-suicide/assisted-dying were brought to the high court, all of which were denied.

of choice – and its association with rationality and autonomy – in current healthcare

practices, and I discuss these critiques further in Chapter 4. Mol proposes that the approach

of managing disease through a logic of choice is different from approaching it through a

logic of care in that it places patients in a position to care for themselves as individuals even

when they are embedded in a complex set of practices and relationships that shape their

disease as much, if not more, than their choices to monitor and manage it does. For the

purposes of my discussion here, I wish to outline how choice and care are often positioned

as opposites and the implications this has for studying end-of-life care that is rooted in a

discourse of both choice and care.

Since the 1990s, there has been an increased emphasis on patient/individual choice within

the English National Health Service, which has to lead to patient-centred care. Patient-

centred care involves focusing on the individual patient's preferences, wishes, needs and

values when making decisions about healthcare treatment; in ethical terms, patient

autonomy is the primary value attended to. 'Real choice' was framed within healthcare

policy and literature as being able to make decisions about where and when care is

received, what service one accessed, and how someone wished to treat or manage their

condition. "The Choice Consultation" in England during the early 2000s explicitly stated that

"offering choice is not an end but a means to improving patient and user experience – a

means to empower and enable [them] and professionals to make shared and sustainable

decisions, to enable the NHS and social care to deliver a service that is more responsive…"

(DH 2003a:3). During this time, as Greener has noted, a focus on service responsiveness and

collaborative doctor-patient relationships reflects the "subtle and cumulative manner" in

which consumerism became part of healthcare policy (2009:309). Framing choice as a key

objective therefore changed the way services were delivered, both on a systems level but also on the interpersonal level of clinical interactions. It is this approach, underlined by consumerism, that Mol labels the logic of choice. A main feature of this is that individual patients are positioned as potential consumers of healthcare, who are to seek out and manage their own treatment. Patients become experts of themselves and are viewed as active agents in their health, individually responsible for their condition, within a system designed to respond to demand.

The shift towards patient choice is often framed as a move away from medical paternalism (Coulter 2002). In this way, choice (as a stand in for patient autonomy) is set up as antithetical to doctor-lead care. Paternalism is characterised by 'the doctor knows best' mentality where patients are pictured as unquestioning and passive recipients of care, and decision-making is largely based on the ethical principle of beneficence. From this, care is driven by a concern about the patient's overall welfare. Critics have suggested that an emphasis on patient choice may marginalise health professionals' ability to advocate for care based on best interests, which is presumably informed by the medical training, in lieu of following patient demand (Foster 2009). Paternalism is therefore cast within this body of literature as caring and inter-relational, even if the word itself has become 'dirty' with time. Importantly for some, models based on paternalism place more responsibility for health within the hand of the health service rather than with individuals, and a shift towards patient choice is seen as an abdication of this responsibility (Mol 2008). Care is therefore inherently political as well as medical.

This dualism between care and choice, however, is rather simplistic. Not only within the policy discourse but also in how health professionals relate to patients, choice is viewed as a

vehicle for care rather than standing in opposition to it. This is a point that I explore further in Chapter 5. Nevertheless, orienting a service towards one value over the other – such as the emphasis on patient choice within the National Health Service – shifts the way healthcare is delivered, with unintended consequences, and this is the point Mol is emphasising in her book. For her such changes in the delivery of health services will not result in the outcomes desired by policy because a focus on choice fails to embody the complexities of living with chronic conditions and the inability to make best-interest choices all the time (2008:2). Instead she suggests that an emphasis on care where needs are negotiated, rather than assumed by either side. Although I am interested in end-of-life care rather than managing a chronic condition per se, her example of chronicity and management epitomises how health is viewed in a contemporary context as an on-going project, which can also be said of the current end-of-life care policy stance towards dying, as I discuss in Chapter 3. So whilst choice and care are provocatively oppositional in these debates, I wish to play on this opposition in a more subtle manner through the structure of this dissertation, illustrating the enforced nature of choice, the different kinds of care and ways care are alluded to, and the inter-relational ways of doing care and choice.

1.6: Outline of Dissertation

An overview of the National End-of-Life Care Strategy in light of anthropological thinking and critiques of choice and care raises several questions about death and dying in contemporary England. In this section, I outline the research questions and how the dissertation is structured. Overall, this dissertation explores choice ethnographically in relation to English end-of-life care with a focus on relations through an exploration of policy, practices and experiences. I contrast different notions of personhood as they are created and experienced through relationality. Due to the scope of the study area, each chapter

deals with a specific empirical issue and set of related literature; these are all linked through an interest in relationality, including the connections and disconnections between persons, objects and concepts.

1.6.1: Research Questions

There are three main research questions addressed in this study. The first is what is 'end of life'? I probe the corners of this question in Chapter 3 to show how end of life is defined, by whom and how it is employed, and I revisit this issue in Chapter 7 when exploring people's experiences towards the end of life. Secondly, I am interested in how 'end-of-life care choice' is done, which is the focus of Chapters 4-6. Throughout I address how end-of-life care and choice affect the way people relate to one another, themselves, and material objects or concepts, both of which I take to be interactive agents.

1.6.2: Structure of the Dissertation

The structure of this dissertation mimics my journey through these topics and the field of English end-of-life care. The opening excerpt before this chapter provides insight into how I first approached the research topic, and in between sections, I have included more extracts as a way of showing the rawer edge behind the more polished chapters. The arching nature of this piece is that I begin with a focus on practice and move towards experience, including reflexive accounts, all the while toying with the notions of choice and care. I have divided the dissertation into four sections to artificially segment this progress, starting with background information in Part 1 including an outline of the study and methodology. In Part 2 I look at end-of-life care and choice primarily from a policy and healthcare practice perspective. Here I unpick the concept of end of life, and how the dying person is defined in current policy in practice, as well as 'choice' in the context of EOLC and how choice is constructed, using the case example of the Preferred Priorities of Care document.

Furthermore, I explore how relating to persons as dying is shaped by EOCL policy in clinical encounters and the implications this has for the kinds of work healthcare professionals, particularly nurses, do.

In Part 3 I move to describe the experiences of those who may be considered 'end of life', drawing primarily on interviews and participant-observations in people's homes. Whilst these experiences are bracketed off from the discussion of EOLC in policy in practice here, I am over-emphasising this disjunction in order to make a point about how holistic healthcare policy does not, and perhaps cannot, capture all aspects of people's lived experiences even when attempting to manage dying. Moreover, these accounts seek to question the taken-for-granted notions of death and dying that are embedded in current EOLC policy and practice. Lastly, in Part 4, I discuss the implications of these findings further, both theoretically and practically. In particular, I explore the concept of personhood further and how shifting to a more diffuse concept of the person has implications for understanding choice and death.

Overall, this dissertation outlines the key concepts of English end-of-life care after the release of the National End-of-Life care strategy in 2008 and explores how these concepts are mobilised in healthcare practice. Through a focus on relationality, I outline how these concepts shape the way healthcare is delivered, and in contrast, how people focus on daily life rather than declining health. Consequently, I demonstrate how what can be understood as 'end-of-life care choice' is more a reflection of the relationships a person is part of rather than their individual autonomy and that in spite of policy's emphasis on planning ahead, people are faced with managing an uncertain phase and the possibility of changing relations.

Chapter 2: Methodology

2.1: Introduction

As illustrated in the previous chapter, this research focuses on complicated and contested notions – such as choice – that are treated as practical, unquestionable objectives within the health system. Understanding how choice in English end-of-life care has come about and how it operates on a daily basis in practice and in people's lives requires a set of techniques that can simultaneously be embedded within those practices whilst taking the wider context into critical account. Anthropology - as a discipline with a tradition in social theory and methods - is well suited to this task as it seeks to understand the world from the point-of-view of those operating within it whilst also relating the perspectives to other operations and values that may relate to it and impinge on it. By using anthropological methods and social theory to examine meanings and practices, these constructions can be disentangled. This chapter outlines the methods used, based on ethnography, to understand choice in the context of English end-of-life care.

Anthropologists traditionally use a variety of techniques under the umbrella of ethnography to research and write about their subject. Ethnography is a way of setting a research subject – whether it be an item, person, thought or behaviour – against the widest possible backdrop of other thought and custom (Carrithers 2005:436), by studying language, practices, and interactions in-situ as much as possible. This is primarily done through participant-observation and informal discussion with informants, key people that are involved in the subject under study. It can also involve more structured interviews, analysis of written texts, and taking part in activities (Bernard 1998). Additionally, ethnography is a

particular way of thinking about presenting research in a descriptive and discursive way

(Clifford and Marcus 1986). The details of the methods used for this study are in the

sections below. What is important to remember is that the methods one employs should

suit the questions asked. In this study, because I am interested in the what, how, and

experience of choice and end-of-life care, ethnography provides the tools to explore these

issues in a manner that sets the concepts and practices against the values that influence

them.

A central tenet of ethnographic research is that the researcher spends an extended period

of time immersed in the society and culture that are part of the study. Often this involves

travelling many miles to live with a remote tribe, but it can involve ethnography 'at home'

(Messerschmidt 1981; Jackson 1987).[13] More recently, ethnography is often multi-sited

(Marcus 1995; Strauss 2000; Ong and Collier 2005), which involves spending shorter

amounts of times in several settings but still focusing on the same subject or practice and

exploring how it links across time and space. What is important is the intense time

commitment of the researcher to be connected to the research subject, willing to be

entangled with it for months at a time on a daily basis. Although the researcher may start

off as an 'outsider' to the community or people involved in the study, this immersion over

time helps to create a certain level of 'insider' rapport, thereby providing another means by

which the anthropologist can understand the subject under study. Similarly, regardless of

setting, the principle behind ethnographic fieldwork is that the subject – whether it is a

practice, custom, or person – is followed and traced through and set against the different

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[13] Although I am not originally from England, I have lived in the country for several years. Many of the research participants classified me as 'native' or did not question my nationality, although some did ask about my accent as it was not 'local'. Moreover, I am familiar with the health system and other cultural references, more so than an anthropologist coming to the UK for the first time.

settings it is found in in a way that sheds light on its meaning. In this way anthropological research, through ethnographic means, is organised around the subject and is consequently flexible, adapting the research in order to follow the topic, which is particularly pertinent as the researcher's understanding of the topic will change as more information comes to light.

An advantage of doing ethnographic research is that as the researcher builds rapport and increasingly understands the subject in new ways, information not otherwise obtainable through formal settings or through direct questioning becomes available. Similarly, by using several techniques including participant-observation and informal conversations, information that might not be containable in discursive states can be observed, enacted and performed (Fabian 1990; Aldridge 2004). This is pertinent for culturally-sensitive topics, such as end of life care, or routinised practices such as decision making, as the nuances that make them up may not be easily captured in more structured and formal settings (Pool and Geissler 2005). More structured conversational encounters, such as interviews, are also employed in order to ask how people make sense of things (Hockey and Forsey 2012:71) and such methods can be socially appropriate in Western settings (Hockey 2002). Additionally, part of doing ethnography is the experiential knowledge the researcher gains whilst in the field as he/she not only listens to what is said, but watches, feels, tastes and smells (see Agar 1980). It is a different kind of 'data' that can contrast and supplement the more formal data collection and make sense of what is it like to live within the parameters of the subjects under study. This information is often contained within the field notes and serves as a rich bed of reflective thought. Overall, through the various ways of doing fieldwork – the different techniques used to gain information and the embedded nature of

the research – ethnographic research provides a wide range of information and data that can later be analysed and written about.

An ethnographic approach that places the objects of study in everyday practice and discourse is suitable to study the relation of choice and end-of-life care in policy, practice, and people's experience. This chapter outlines some of the key features of the ethnographic approach used for this study, including: the scales of field sites; the details of the method; and encounters that shaped the design and execution of the research. At times, I have also discussed the ethical and reflective aspects of conducting research into end-of-life care in England, related to how the topic is conceptualised and the ways personal and professional boundaries are managed. Some of the issues raised in the sections below, such as the practical implications of categories and the importance of relations, are also evident in the following chapters, demonstrating an analytical flow between methodology and interpretation.

2.2: Locating the Field and Fieldwork

This section outlines the scales of the 'fields' of this study as well as describing when and where this research was conducted. I begin by describing how this work fits within a wider remit of health services research within the United Kingdom, and the expectations and tensions this can create. I then briefly describe the healthcare landscape in England, primarily marked by the National Health Service (NHS). Lastly, I map out the local context in which the research was conducted and how this setting shaped the study. This research is based on work conducted between 2010 and 2013, during which there were considerable changes to the organisational structures of the NHS. Fieldwork in the form of clinical

shadowing of health professionals, participant-observation and interviews occurred

between late 2010 and early 2012.

Health services research is an interdisciplinary field concerned with how people access

and use healthcare services and the outcomes of this. Medical anthropology delves further

in that it is concerned with the meaning and experiences of people's interaction with their

health and healthcare services. Funded through the National Institute of Health Research as

part of a Collaboration and Leadership in Applied Health Research and Care in the United

Kingdom, such research is expected to have direct application in order to improve services,

access and outcomes, and typically impact should occur within five years. This has created a

particular set of parameters and tensions in terms of how the research is conducted and

framed. Rather than adapt an action research method approach in an ever-changing field,

the 'applied' aspect of this study is more subtle and focuses on understanding practices and

experiences instead of re-shaping them.

From an anthropological perspective, understanding the context in which the study is

conducted is part of the wider field; in this case, it is about understanding how the research

is conceptualised and intended to be utilised – health research's main purpose is to improve

health outcomes. At times this emphasis on changing services, driven by the funders, policy

makers and some colleagues, has been frustrating as it boxes out the moral aspects of this

(e.g. who is deciding what outcomes are best?) and the sometimes premature link between

observations and 'results'. Throughout this study, my primary purpose has been on

understanding what choice and end-of-life care are, rather than creating ways to improve

choice within end-of-life care. This does not mean that the findings cannot have

implications for how end-of-life care is conducted, and these comments can be found in

Chapter 8. This distinction is important as it pertains to how the research was conducted, focusing on an ethnographic approach collecting qualitative data, rather than employing other methods that would be part of actively changing the landscape under study.

Speaking of landscape, the English healthcare system is organised primarily around the National Health Service (NHS). The NHS was established in the late 1940s to provide state-funded (through taxation), equal-access healthcare to the population to reduce mortality. Today, health care – that is services directly related to issues of medicine and disease – is provided free-at-the-point of use to those who live within the United Kingdom.[14] Care classified as not being directly related to disease – known as social care and can include help with getting dressed as a consequence of general frailty – may not be provided for free by the state.[15] The way the wider care system works highlights the practical importance of categorisation, an issue discussed more in Chapter 3. The main element is that although health insurance does exist in England, the majority of health care is provided and organised by the NHS where the cost is born by the State rather than the individual.

For context, there are several key elements about the NHS that I wish to highlight here as these relate to the descriptions in the following chapters. People are registered as patients with a general practitioner (GP) practice that is part of primary care, and it is to GPs that people will initially present symptoms to and who will refer the patient to secondary care, often a specialist service located in a hospital where more technical diagnostic tests are performed. Patients with chronic conditions are to be assigned to a specialist team, often containing nurses and consultants, that may be located either within primary or secondary

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[14] There is some difference in delivery between England, Wales, Scotland and Northern Ireland.
[15] This division of health and social care is currently (at the time of writing) being reviewed by the government. Social care is funded by a combination of government funding through local councils, charity, and private funding. Health care funding is almost exclusively State provided. Care homes are classified as providing social care.

care or both. For example, patients with chronic obstructive pulmonary disease (COPD) are

under the care of multidisciplinary team for their COPD who they regularly see for check-

ups, medication reviews, and who seek to visit them when they are admitted into the

hospital. In some cases, such as cancer, these teams are supported by charities, such as

Macmillan, Marie Curie or local hospices. For those with several conditions, their care will

be overseen by multiple teams with the GP serving, in principle, as the constant contact that

can assimilate the information produced within these other care teams. If a patient requires

additional healthcare services within the home, such as regular injections of insulin or

wound care, district/community nurses will visit them. These nursing teams are tied to

either the GP practice or the wider primary care service in the local area. Patients may also

have care delivered in the home post hospital discharge; this may include a mix of health

and social care depending on the 'care package' agreed before discharge and what is

available within the local area. Lastly, some patients are referred to hospice care in order to

provide more comprehensive symptom management. Hospices originally arose outside of

the NHS system as a way to challenge the way dying was handled; today many are at least

part-funded by the State to provide services under the NHS (James and Field 1992).

Although the NHS is a national service and policy is created nationally by the Department of

Health, the actual services available vary across localities in what is frequently referred to as

"the postcode lottery" (e.g. Vogel 2011).[16]

   This study is concerned both with the national policy and the local interpretations of this.

The local area of study is a county within the East of England, renowned nationally for its

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[16] National policy is applicable to all localities; however there is some scope due to the way services are commissioned that allows for variability in order to match service provision to the local population. In 2013, after fieldwork was completed, commissioning shifted from a region-basis to one based on GP consortiums (Ham 2012). An anticipated consequence of this is that the co-ordination of services may be more difficult due to the smaller scale on which services are being commissioned.

good end-of-life care because of its low rates of hospital deaths.[17] During the course of the study, commissioners were changing the level and scope of their end-of-life care services to improve them further. In terms of geography and socio-economic status, the county is diverse but the majority of the population identifies itself as White-British. There are notable divides within the county, with the north being poorer and more rural whilst urban areas are better-educated, wealthier, and have easier access to a wider range of health services. Due to the small numbers in this study, I make no claims to present a representative sample of the county's population here although I travelled throughout the county as much as possible to provide a sense of the diversity, as well as similarity, of the experiences I report.

Within the county, different field sites were visited depending on the element of the study (described more in the next section). Healthcare services included a large teaching hospital in the main city, a smaller specialist hospital in the countryside and smaller regional hospitals in towns. These hospitals varied in terms of the level of intervention they provided and many people attended whichever hospital was closer (except the specialist one) to them for routine care and emergency visits, and sometimes this would be over the county boarder. There are two hospices, both in the larger cities/towns, and several smaller specialist palliative care centres tied to the regional hospitals; in total, there were three palliative care/medicine hubs. I visited and shadowed clinical staff attached to intercity, town and rural GP practices, including attending home visits in the various sub-regions of the county. I also visited six care homes in different parts of the county, one of which specialised in learning disabilities and another in dementia. In addition to the formal health

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[17] See for example NEOLCIN 2012; see Chapter 3 for an explanation of why hospital deaths are avoided within EOLC.

and social care institutions, I attended local and charity disease-related support groups that were held in places as different as purpose-built centres to town halls and cafes. Lastly, I spent a considerable amount of time in people's own homes and in places they would regularly frequent, such as their favourite restaurant. In this way, rather than conducting research within a single field site, which is more typical of conducting anthropology 'at home' where the research is confined to a particular institution (e.g. Lawton 2000, Kaufman 2005, Powers *et al.* 2011), I took the wider health and care landscape, including people's personal spaces, to be part of the ethnographic field.

Map of County:
Grey dots represent cities and larger towns. Most of the county is rural with smaller towns and villages.

Large star represents the large teaching hospital.

Medium stars represent regional hospitals.

Small star represents the specialist hospital.

Not to scale and the shape of the county has been altered.
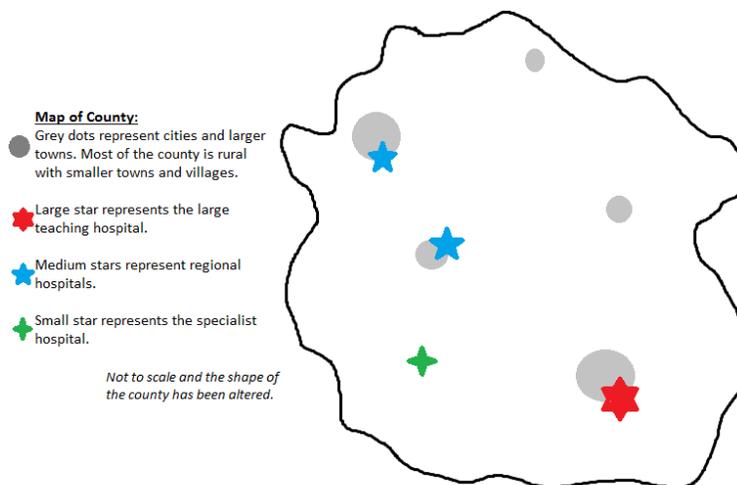
Image 2: Generalised map of the county to represent the distribution of hospitals and the relatively large proportion of rural landscape.

Overall, there were three main scales of field within this research. The first one is the national one in which research and policy are more generally defined. The local scale is county-based and encompasses a diverse region in terms of health care service provision and population. The more refined scale is down to the institutional level, even to the point of the person's home. This periscope effect is replicated in the following chapters in which I begin with a more national-level focus and move down to individual experiences. Since this research was conducted in the wake of the National End-of-Life Care strategy, changes in

national and local government and governance, and in the contexts of people's individual life courses, the parameters and practices were continuously changing.

2.3: Methods

Above I have briefly described the purpose of ethnography and the context of the fieldwork this research is based on. In this section, I outline the specifics of the fieldwork, including how 'the data' was collected. I put 'the data' in single quotation marks because of how this term can be used within research methods and reports, often setting the data apart from the researcher, presenting data as an object to collect irrespective of the researcher's relationship with it or the wider context in which the data is found (see Engelke 2008 for similar argument about evidence).I wish to challenge this positioning of data as being separate from its context and the researcher, by stressing the subjective nature in which 'data' is created and that this can extend beyond the temporal and spatial boundaries of research, as my field diary excerpts allude to. This section therefore outlines the technicalities of generating what can be considered data.

   In 2010, I undertook a period of research design and rapport building within the local community. This included shadowing healthcare professionals in potential field sites.[18] From this, three main elements to this research were developed: a review of the policy, observations of health care practice, and learning about experiences and views through interviews and long-term engagement with people with long-term and/or terminal conditions and their families. Additionally, I kept regular notes in the form of a field diary,

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[18] A period of clinical shadowing was offered by healthcare professionals who were interested in the project and wanted to help me formulate my ideas. The term is one often used to describe the practice of medical students following senior professionals as they go about their daily practice and patient interactions. Since this activity is routinely done with students and I was not directly talking to patients, this period was considered to not require approval from an ethics committee as it could be classed as 'education' or 'evaluation', both of which do not require such approval or formal documentation. During this period I was very much lead by these professionals and patient-consent for my presence was sought by the professional prior to my arrival.

which reflect my thoughts on what I was seeing, hearing and experiencing. Together this combination of qualitative data allowed me to set choice within the context of end-of-life care and people's daily experiences towards the end of life.
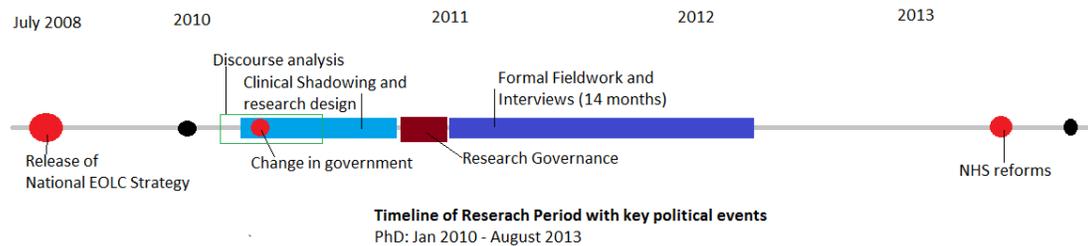
Image 3: Timeline of research period with key political events

2.3.1: Pre-fieldwork and Developing the Research

Visiting field sites before formally conducting fieldwork is useful way to ease into research and reform project design.[19] In order to test earlier research questions and develop the protocol, I shadowed health professionals involved in palliative and/or end-of-life care[20] including Macmillan nurses, district nurses, hospital specialists, and spent time in a local hospice. Some of the people I met along the way invited me to attend local support groups for different people likely to be facing end-of- life choices. I became a regular member of one cancer support group and occasionally visiting a group for people with Parkinson's disease, attending monthly to chat with people about their lives. Not only was I able to have an idea of the practices and issues I would later observe, but I could exchange my ideas about the research with people who could be potential participants. Having to defend my thoughts, brainstorm new possibilities, and listen to their comments was an invaluable experience and highlighted the iterative process that ethnographic fieldwork can provide.

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[19] See Halstead 2012 for an example of how such visits can inform future research; in this paper a chance discussion with a taxi-driver proved insightful for understanding the importance of a television drama in daily life.
[20] The distinctions between these terms can be found in section 3.4 and in Appendix 1.

Whilst eventually none of these people became 'participants' of the main study, their stories and the experience I had working with them helped change the research focus from a more deconstructionist approach based on policy alone to one focusing on people's experiences. Therefore, although not a 'formal' part of the fieldwork, in that it was not classified as 'data collection' by my department, the encounters I had inevitably informed the research question, design, and consequently the analysis.

   One of the key lessons from this pre-fieldwork period was how difficult it was to define the end-of life-period concretely for the people healthcare professionals routinely cared for. I discuss this difficulty more in Chapter 3; however, here it is important to note that this shaped the way recruitment was conducted. Patients who were confidently identified as "end-of-life" during my initial observations mainly had cancer and were expected to die within the next three months; however my access to such patients was often limited by healthcare professionals who sought to protect the limited time these people had (this is discussed more below). Speaking to bereaved carers and palliative care professionals, whilst they valued research in this area, they expressed a concern about "adding another person to the mix when so much is happening", particularly to conduct in-depth, long-term research. It was suggested that meeting people "earlier in their journey" would enable me to have the access to both the people and the practices I was interested in. Moreover, this would potentially allow for witnessing when people "become end of life". However, this had implications for recruitment in that participants for one-off interviews or the long-term study could not be readily approached using palliative or end-of-life care registers.[21] Due to

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[21] The reasons for this are multi-fold: not all GP practices were using registers; many people who die are not on such registers (Thomas *et al.* 2012); registers may not include people suffering from non-malignant disease (Smith *et al.* 2012); and once on a register a patient has already been identified as being in their last year of life and often in the last months of life (Ipsos Mori 2011).

this, and wishing to avoid any pressures to participate that may arise through recruitment

via healthcare professionals (Dean and McClement 2002), I chose to recruit most non-

professional participants through support groups. This way of recruitment was helped by

the rapport I had developed in the pre-fieldwork stage with several of these groups. In this

way, the research design was informed through this exposure to the field prior to

'fieldwork'.

Much is made of patient and public involvement (PPI) in medical and health research and

practice (Tritter 2011), and whilst it is often visualised as a formal process, this scoping stage

of this project served to create the involvement PPI intends to embody without formalising

its process. There were several people who were quite interested in the research from an

early stage, sharing their life experiences and views with me, discussing ideas about how

different topics could be researched, and even commenting on the formal documentation

eventually used in the research study as part of participant recruitment. It was through this

dialogue that the participant information sheets (not aimed at policy makers or healthcare

professionals) were phrased around 'care and decision-making' rather than choice and end-

of-life care (a copy of the information sheets and versions of the consent form can be found

in Appendix 2). It was felt that these terms were less abstract and alienating for the

intended audience whilst still allowing for similar observations and conversations to occur

as the phrases are closely linked (see Orprett Long 2005 for a similar approach). In this way,

the research was adapted to be appropriate for the cultural and personal contexts of those

taking part.

2.3.2: Methods of Uncovering

Earlier I discussed how the research design was informed by a pre-fieldwork stage, which helped to refine the research objectives and methodology. Overall, there were three ways I approached the research. Whilst I outline them here as independent aspects of the same project, there was often overlap, especially in interviews as people opened up about their own experiences or made comments about their opinions about policy and practice. Appendix 3 provides an overview of the data collection and analysis in terms of interviews and observations. The three parts follow the pattern of studying policy, practice and experience.

The first way sought to understand choice and end-of-life care from a policy perspective – to 'follow' choice through policy. For the purposes of this research, I understand policy to be both formal documents that establish guidelines or a position for practice and how these are translated into practice. I applied a discourse analysis approach that involved perceiving language as not transparently reflecting reality but rather constructing and organising that reality (Tonkiss 1998), creating and restricting what can be known, said and experienced at any socio-historical moment (Young 1987). I used a Foucauldian-influenced discourse analysis destabilising the meaning of rhetoric and practices, to question their essence and the way they came into being. Consequently, in Chapters 3 & 4 I was able to illustrate 'end of life' and 'choice' are not given, but have a particular purpose, influence practice, and meaning that is historically and culturally situated.

There are several key Foucauldian ideas that can be drawn on and influence my interpretation of the policy. Firstly, his notion of discursive practice to denote the historically and culturally-specific set of rules for organising and producing different forms

of knowledge (Foucault 1972). These are the rules that allow certain statements to be made and construct the object that can be known. Secondly, his idea of gaze illustrates that through 'knowing' (or observing) the object, the 'knower' is also constructed (Foucault 1973), indicating that power is relational and both repressive and productive. Thirdly, technology is the regulation of a particular objectified human practice through a set of objects, rules, conduct or disciplinary apparatus (Pels 2000:137); in particular, technologies of the self that allow individuals to transform themselves into a desired state of being by carrying out operations by themselves or with the help of others on their own bodies, souls, thoughts, etc. (Foucault 1988). Together and following Shore and Wright (1997), I question how policy is a cultural agent that constructs subjects as objects and creates new subjectivities. Together these ideas link discourses to practices, illustrating a connection between thought and action that is implied in the process of creating and implementing policy.

The policy documents I analysed were mainly Department of Health documents from 1997 onwards, particularly focusing on policies related to choice since 2000 and especially the End-of-Life Care strategy (DH 2008). I also examined several historical documents to see when and how choice was mentioned and how the concept evolved over time in formal documentation.[22] Additionally, I observed and made fieldnotes about seven policy-related events from 2010-2013 that focused on end-of-life care in the UK and changes in practice since the release of the End-of-Life Care strategy. Furthermore, I conducted 12 semi-structured interviews with people involved in the development of policy, including those

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[22] I focused mainly on publically-available formal documentation as this is what is provided to healthcare professionals and commissioners. I also looked at related documentation produced by third-sector organisations, such as Marie Curie, to see if and how discourses are shared between sectors. In some occasions, when interviewing policy makers, I had the opportunity to view documents that were used during policy formation (e.g. drafts or minutes of meetings) and these confirmed the evolving nature of the choice discourse and how policy is an act of negotiation.

working within the national bodies developing documents, third sector organisations

advising government, and local commissioners. These individuals were identified, selected,

and approached by me based on my knowledge of their involvement in the policy process;

needless to say, not everyone approached took part in interviews but most did or suggested

someone else in their organisation that could. Most interviews were conducted face-to-face

in their place of work in order to facilitate the meeting and provide context to the

comments they made about their working environment, and to allow them to have access

to impromptu and unsolicited prompts during the conversations, such as key documents.

The majority of conversations were recorded with minimal note taking to encourage a more

conversational approach – when concluding the sessions many commented on how easy it

was to talk, how they felt they may have rambled as they covered so much, and that it was

useful to be asked to assemble their thoughts about the topic and policy process. Together

all of this information was analysed to identify what the key messages in policy are (e.g.

what statements are repeated and emphasised), how they are created and what evidence is

used to support them, and the underlying values represented in EOLC policy.

The second element of the research, which formed the majority of the 14 months of

fieldwork, was to understand what care and decision-making meant from people's everyday

perspective, including the perspective of healthcare professionals. In particular, I was

interested to hear from those who are suffering from long-term and life-threatening

diseases and/or those caring for them. Based on the feedback received during the pre-

fieldwork phase, I approached various disease-related support groups and hospices

throughout the county. With the group leader's permission, I attended the meetings and

briefly presented the research, asking volunteers to take part in either a one-off interview at

a time and place of their choosing, usually their home but sometimes a cafe, or in a long-term study (see below). I also continued my clinical shadowing more formally within hospitals and a hospice to supplement the interview data. This part of the research was aimed at understanding if and how policy was being implemented in practice and how people negotiate their understandings about what care, choice, and illness/dying mean in a practice setting.

I interviewed over 30 individuals/couples recruited through these support groups and/or hospice day therapy using an informal, conversational approach (Kvale 1996). Most were either suffering from a long-term condition, likely to be 'terminal', and/or were caring for someone in this position.[23] Healthcare professionals were approached personally based on my knowledge of their interest in palliative and end-of-life care or regarding their relationship with a patient in the study; in total I interviewed 13 professionals including two general practitioners, one hospital consultant, two Macmillan nurses, two district nurses, three hospice nurses, and three other specialists. These interviews were structured as professionals may expect a more formal exchange (Odendahl and Shaw 2001). Social care professionals were also approached using the same method but none took up the opportunity to be interviewed; observations in care homes were conducted as part of the long-term study and I conducted several informal conversations with social care professionals as part of my recruitment of carers. Interviews lasted between one to four hours and most were audio recorded with the participant's consent with handwritten notes made throughout; this data was supplemented by fieldnotes about the setting, interaction

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[23] I also spoke to four individuals specifically about assisted dying; these people had written letters to the editor in a local newspaper about the topic at a time the issue was being raised within the research more generally so it was decided that this might be an interesting side avenue to explore even if it would not form a major part of the research.

during the interview and any other relevant information (see Appendix 3 for an example of how fieldnotes may look). Interviews, and the intense listening that is part of them, enabled me to engage with participants and to understand their experiences from their own perspective (Holy and Stuchlik 1983; Hockey and Forsey 2012).

The third element of this research is a continuation of the second element, but is based on a longitudinal engagement with a sub-group of people who opted and were deemed suitable, for the long-term study. The purpose of following several people was to see how their experiences, interpretations, and relations might change over time. These individuals all had long-term conditions which could present the need or desire to think about the future and do advance care planning; in some cases it was likely that they would be 'end of life' and die during the course of the study (which two did). There were 10 people (plus partners/spouses in four cases) in this part of the research and summaries of those discussed in detail within this dissertation can be found in Appendix 4. I visited these participants between five and 25 times during the course of the fieldwork, this period lasted anywhere between six weeks to 13 months depending on the person and their situation. The visits – or meetings – occurred in a place of their choosing, usually their home but occasionally in cafes or care homes. Such visits involved a mix of conversational encounters, ranging from informal chats to more structured questioning, as well as participant-observation. In addition to the visits, we also spoke on the telephone and/or over email, I accompanied them to doctor consultations and hospital appointments, met and interviewed those involved in their care both privately and professionally, reviewed their medical notes, and took photographs of them and/or their setting. How frequent we met, where we met, and what we did (and what I had access to) was quite flexible and was often

reviewed and discussed. Additionally, if someone was admitted to hospital or their circumstances changed, I checked with them if they would like me to continue visiting.

The long-term participants were all from the local area under study and considered themselves to be from a (White) British working or middle-class background. Their ages ranged from early 50s to late 90s and their conditions included cancer, motor neuron disease, dementia, Parkinson's disease, COPD, and general frailty; it was not unusual for them to have more than one condition and for their partner, who was often their informal carer, to also have a long-term condition. I mention these demographics to illustrate the range presented and to demonstrate that the research is not intended to be a statement about how people with one or another particular disease understand the issues. Instead, the research is more about how the issues are confronted more generally, because of one's declining health status, and how people are dealing with and understanding care, choice and dying.

Together the three elements help paint a picture of what choice means in relation to end of life care. Individual interviews, interactions, or observations were analysed as well as case summaries for each person in the long-term study, which could be compared to identify translational themes and similar occurrences. As key events or themes became evident to me, I wrote notes about them and tried to explore them further in my conversations and observations. As this process progressed, I began to make links between these issues and to think about the wider concepts and ideas that they could relate to. This was an iterative process and continues to unfold.

Since writing ethnography is an interpretive process (Tedlock 1995, Clifford and Marcus 1986) and involves making sense and giving order to a thick detail and description of one's

data (Geertz 1973), the final product is not a mere product of what was observed, heard or documented, but a configuration of how these interact with one another and the meaning they have both in their own cultural context and in terms of thinking about one's own society and wider human possibilities (see Marcus and Fisher 1986). In several of the chapters, the examples I draw on come from the participant's narratives of events rather than descriptions of events witnessed. Rather than emphasise the dialogical or structural processes of narratives (Moen 2006; Atkinson 2009) or present these statements as uncomplicated assertions of what one truly thinks, I have interpreted what was said, as well as how it was said and the wider context, to explore the assumptions and meanings embedded within the narratives (see Sinclair Bell 2002; Josselson 2006). The interpretative process of ethnography then is one of shifting between layers of accounts and making connections between them. Anthropology therefore provides a way of presenting a narrative about something (see Westerhaus 2007) – in this case choice in relation to English end-of-life care by drawing on people's perspectives, observations of practice, and the policy literature.

 Each aspect of the research could stand alone and be presented as such. However, the intention of doing such a wide range of data collection was to explicitly try to resist some of the institutional and disciplinary boundaries applied to end-of-life care where policy, practice and experience are separated or data from different sources are treated independent of one another. Therefore, different parts of the study weave into one another and have informed the interpretation of one another. The scope of the data is demonstrative of setting a subject against the widest backdrop as possible whilst also maintaining a focus to allow the subject to be interrogated comprehensively.

Ethnography provides a way to study choice in the context of end-of-life care by placing an abstract idea into a web of practices, discourses, and experiences. Moreover, it provides a way to describe these intersecting contexts using description, as evident in the following chapters. Due to the complexity of the lived world, the different kinds of data feature in the subsequent chapters together, although in some cases, such as in Chapters 3 & 4 which focus on policy, there is more of an emphasis on formal discourses whereas Chapter 5 describes practices, and Chapters 6 & 7 are drawn primarily from the long-term part of the study.

2.3.3: NHS Research, Development, and Ethical Issues

In this section, I discuss some of procedural and ethical issues raised by this research. Firstly, I outline the bureaucratic elements to conducting this research, which are different from the methods discussion above, but include explaining an 'unfamiliar approach' – ethnography – to committees accustomed to clinical trials. I then outline aspects of assessing capacity to participate and the process of consent. Whilst this discussion is not exhaustive of the issues confronted in this research, and more is discussed in the next section and Chapter 8, it serves to highlight the tensions of conducting fieldwork in the UK healthcare system.

Since this research was concerning people who were treated by the National Health Service (NHS) and the observations I conducted were often on NHS property, the study protocol had to be granted favourable opinion by a NHS research ethics committee (REC), which was approved in 2010. Many RECs are unfamiliar with the ethnographic method and at the time of application, the forms researchers must use were designed for quantitative research and randomised controlled clinical trials. It was within this restrictive framework of

risk and quantifiable patients and data that I had to outline the unfolding and unpredictable

nature of ethnography, particularly since I was 'following' people and could not anticipate in

advance what activities I would be part of. In order to present this as a valid method, I

emphasised the person-centred nature of this approach, borrowing the language of medical

policy and PPI, and evidence of previous similar (successful) projects conducted in

comparable settings. In this manner, I was able to highlight the flexible, sensitive and

appropriate nature of the ethnographic method to the subject area and research questions.

   In addition to REC approval, each separate NHS site – such as a hospital or group of

general practitioner surgeries, needed to review the research proposal and grant permission

to enter their premises and interview their staff. This permission is called Research and

Design Approval (R&D) and in total I had to apply to nine different health trusts plus the

local social care body. Although the paperwork I submitted was identical for each location, I

was not permitted to do all activities at each site; for example, one trust refused to allow

me to take photographs. Moreover, even with official formal approval to conduct research,

access was not always readily granted 'on the ground' as doctors, nurses, and

administrators served as another layer of gate-keepers. Where possible, such as a planned

accompaniment to a clinical visit, I contacted staff in advance to inform them of the study.

This on-going process of gaining access demonstrated that although there are formal

procedures in place to enable research within the NHS, local practices – even at ward-level –

can impact what kinds of research are possible to conduct.

   One aspect that is part of the REC and R&D forms is the involvement of participants who

may lack capacity. They are deemed unable to independently decide to take part in

research. For the purposes of this research, patients who were under 18 years of age or had

severe dementia or learning disabilities were not recruited. While it is likely that a study of these groups would shed light on the conditionality of autonomy, it was beyond the scope of this study to involve such participants. However, this does not mean that capacity was not an issue during the fieldwork. There were times when participants were asleep or unconscious when I visited, especially in the last week before death. In these instances the decision to record those visits as 'data' was based on our previous relationship, my understanding of what they considered to be part of the research, and how their families felt about my visit. In some instances, I was able to obtain consent for such visits before they occurred. Even if I did not make notes about a visit, it is hard to forget the experiences of 'being there' with them in those last hours. Capacity to be part of a study and capacity to be part of a 'relationship' are therefore different things and this is a theme I explore further in Chapter 8.

Similarly, there was one long-term participant, Albert,[24] who had a mild form of dementia where he was often "okay but occasionally disoriented" as his care home manager explained. Since the End-of-Life Care strategy applies to those with dementia, and by living in a care home Albert was facing end-of-life care issues, I considered him eligible for the study. After meeting him several times, and ascertaining that he could comprehend the purpose of the research, I included him in the project. However, near the end of the fieldwork period and following an acute infection, he began to display signs that he only viewed my visits as social ones and prioritised this relationship over the notion of conducting research. Due to his change of attitude, which indicated that he no longer comprehended the project or his involvement in it, I wound down his participation and

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[24] All names used in this dissertation are pseudonyms.

informed the care home of this. This case demonstrates that capacity to participate can change with time and circumstances, and that researchers should be receptive to this.

Another aspect of research that combines a concern for procedure with a practice that is more process-based is that of gaining informed consent from participants. Within healthcare research, written consent is the ideal and copies of the consent forms to be used must be submitted to the REC with the study protocol. In observations, however, it is not always practical or appropriate to obtain written consent for every person in the room (Plattner 2006), although were possible I made my presence and intentions knowable. For interviews, in most cases I was able to obtain written consent prior to the interview, although I would also accept verbal consent to be followed by written consent after the interview had ended. 'Obtaining consent' can often interrupt the follow of conversation, which often starts as one is met at the door, and allowing participants to review their consent to the project at the end of our conversation provided them with an opportunity to reflect on what had transpired and if they were comfortable with their stories being considered as data. For those involved in the long-term study, written consent was sought at the start of the study and verbal consent sought throughout to reaffirm their involvement and voluntary participation. Anthropologists have often argued that the obsession with written consent does not adequately reflect the nature of engagement in research (Barrett and Parker 2003; Corrigan 2003) and by allowing consent process to be less rigid than implied by the use of a form at the start of every encounter, I embraced this relational way of conducting research.

This discussion of ethics and bureaucratic approval based on ethical concerns highlights the procedural concerns of what is ultimately a process between people interacting in the

field of life. The unfolding nature of ethnography, as well as people's lives, can make it

difficult to pre-empt what kind of engagements one will be part of. Nonetheless, through an

open approach that allows for reassessments of involvement, I was able to change the tack

of the study to adapt to this unfolding process, both in my own life and those who were part

of the study, thereby continuing the data collection process. The flexibility and sensitivity of

this allowed for the continual engagement expected of anthropological fieldwork.

2.3.4: Discussion

In this section I have discussed the practical elements of the ethnographic fieldwork – who

was involved, how data was collected and analysed, and working with(in) the bureaucratic

system of healthcare settings. Using ethnographic methods, which involved different forms

of data, data collection, and data analysis, has many benefits and limitations in the context

of this research subject.

  It provides a very rich data set, both in scope and description; however, due to the specific

nature of the method, focusing on fewer individuals without systematic sampling, can make

it difficult to assert generalisation from single cases to the wider population. In order to

address this, as I have done in the following chapters, what is demonstrated through the

material is placed into a wider context about how one thinks about people and life, drawing

and building on theoretical debates. A benefit of using an ethnographic approach to do this

allows me to weave together description and analysis, and using the different kinds of data

to speak to each other and test the applicability of analysis. For example, a discourse

analysis of policy may indicate that choice in end-of-life care is about managing the dying

person through their wishes, whilst observations of clinical practice where choice is done

suggests that it is part of demonstrating care. Therefore, this approach allows for a more nuanced interpretation of the subject area.

Another key feature, which relates to the richness of the material, is the length of the study and the depth of engagement. This allowed me to notice changes over time, to check my initial findings as the research progressed, and to have access to a different understanding than I would have had if I had only met people once (an example of this is in Chapter 6). This process does, however, mean I amassed more data than can be represented in a single dissertation and consequently much of what I learnt is not present within these pages. As with any writing, one must create boundaries around the work and I have kept these to focus on choice and relations, although I also learnt much about what it is like to be a policy maker or healthcare professional, how people deal with the emotional work of end-of-life care, and people's life stories.

One feature of ethnographic fieldwork, which is shared with other qualitative methods, is that it can be considerably time consuming, both in terms of data collection and analysis, and emotionally intense. At times, the former issue has led to contentions with funders and participants – including policy makers – who wish to know results as soon as possible, even the day after the first interview. As with the ethics committee, I have endeavoured to explain the unfolding process of this methodology and provide provisional answers when possible. The latter issue is more one of reflection, and although not often reported (Shrestha 2007; Pollard 2009; Spencer and Davies 2010), I have openly spoken about these issues at several conferences and provide an insight into my reflections in this dissertation through my use of the field-diary excerpts and the discussion of ending relationships in Chapter 7.

Whilst the ethnographic method has its own limitations, it was suitable to answering the questions I had about what choice was and how it was done in the context of end-of-life care and how people experience this. The multi-prong approach of the study involving discourse analysis of policy, observations of clinical encounters, and interviews allowed me to make broader statements about choice and end-of-life care than any one technique alone would permit. This is particularly pertinent as I seek to make more general statements about relationality and personhood, drawn from specific examples, which would be harder to sustain without the kind of rich and varied data that conducting ethnography has provided. Moreover, whilst the ethnographic method may be less well-used within the NHS and health research and has its limitations (such as a smaller sample size and time-length required), I have outlined the benefits of the method in terms of adapting research to the subject matter and how it can enable different ways of knowing. The next section builds on this discussion of methods further by outlining several encounters in the field that both shaped and made known different aspects of the project.

2.4: Encounters in the 'Field'

To provide a sense of what doing the fieldwork was like, this section discusses some of the ways the study was constructed and imagined by others as well as myself, and how these images were negotiated through the course of the research. The romantic idea of a lone anthropologist venturing into the exotic does not reflect the corridor conversations fieldworkers have back at home about how they gained access, made fools of themselves through misunderstandings, and how their research activities were made sense of by those that were 'being researched' (Faubion and Marcus 2009). What I describe here provides an insight into these issues in the context of doing ethnographic fieldwork in England and the healthcare system. Firstly I discuss how potential participants were framed as 'vulnerable

persons' by the ethics committee; this relates to conceptualising the dying patient as discussed in Chapter 3. Secondly, I address the practical issues of access and adapting the ethnographic method to the English cultural context in terms of what is considered private and public. This had implications for the way the research was done. Lastly, elements of performance and managing boundaries, by extending the concept of public/private, are examined and how this has implications for 'what' one is considered to be and to be doing. Overall, this section highlights how research is not just an intellectual activity but is actively shaped by the context in which it occurs and how others engage (or not) with it.

   The prospect of 'vulnerability' was a significant category for and consequence of the fieldwork method I proposed. In the previous section, I mentioned the process of obtaining a favourable opinion from the research ethics committee. Part of the process involved deliberating on and articulating how I would manage the inclusion (or exclusion) of 'vulnerable persons' within the study. When I sought clarification as to who would come under this category, it included: those with learning disabilities, those with dementia, the very young and the very old (without definite age ranges), and those who were considered to be 'suffering' which could include those who were terminally ill and recently bereaved (see Buckle *et al*. 2010; Pleschberger *et al.* 2011). The purpose of this category is to encourage researchers to consider the potential risks research may present for these groups, and whether the knowledge produced outweighs this risk and how the risks may be minimised. In the case of the present study, the committee stated that they were concerned about how discussing "sensitive topics" may leave people "feeling vulnerable" and how I would respond to reactions like crying. Working with a framework of clinical trials with clear interventions, the necessity of talking to people about their experiences was not

self-evident in terms of the outcomes it could produce. Whilst this has implications for how such committees understand research (see Tolich and Fitzgerald 2006; c.f. Hedgecoe 2008), what I wish to highlight here is how death and dying are inherently seen as sensitive topics and through dying, a person becomes 'vulnerable' through their emotions. This is in contrast to how such persons are depicted within policy, and previous research has shown that the body is the main focus and where problems lie (Lawton 2000). As part of the REC process, I was invited to defend my proposal and in response to such questions, the committee openly admitted that "having met you, we are reassured you will handle such situations well". The potential harm from this study was depicted therefore not in what could physically "go wrong" but how it may be emotionally charged, perhaps projecting the committee members' own views about death and dying onto the research. Within palliative care research, this objection to research is not new although there is evidence that people wish to take part in such projects and may even find them therapeutic, although this still draws on the language of harm and benefit (Kendall *et al.* 2007). What this example illustrates is how people are categorised based on expectations and protocols – in this case research protocols – are designed around these categories. This is a theme I explore further in the next chapter.

Notions of vulnerable persons were also evident outside of the ethics committee; who I could visit, especially when shadowing clinicians, was based on the individual health professional's view of what was 'appropriate'. Even though they knew I was interested in end-of-life care, I was often allowed to accompany them on visits to see the more talkative and alert patients, many of whom were aware that they were dying, and those who had fewer open wounds and disfiguration. We spent very little time in the side rooms were 'the

dying' often laid and if intimate personal care was required, I was to leave the room. When it came to recruitment, this pre-selection of suitable persons continued as support group leaders suggested potential participants based on their gregariousness, need for company, and/or relative wellness rarely suggesting I should speak to those they considered to be 'near death' even though I would be interested in talking to these very same people. Not only were people being classed as 'vulnerable' but other values, such as the potential enjoyment they may have from taking part in research, were drawn on in these selections and gate-keeping actions. This is an example of how health professionals balance different social and professional values, and is further discussed in Chapter 5 in the context of doing choice with patients.

The previous issue is part of managing boundaries and this is a theme that cuts across this study. Here I wish to raise a few of implications of this in terms of how it impacted the way the research was done and experienced. The first aspect follows on from observations during clinical shadowing. Often, instead of referring to me as a 'researcher', I was introduced as 'a student', which I was although I was not a medical or nursing student, which was what could be inferred from the label. When asked why they did this, frequently I was told that the latter label was more convenient as patients were used to having students present; it therefore required less of an explanation. Ultimately, those I was shadowing felt that my purpose, as one of learning, was the same regardless of how they referred to me. On the flip side, when I accompanied participants to their clinical consultations, many found it awkward to refer to me as their 'student' or 'researcher', often calling me a 'friend' or 'someone who is interested in my life'. This highlights potential complications in identifying and understanding what research is, and consequently who a researcher is. In terms of

conducting research, it has implications for how overt the conduct of research is. For me, this led to questions about my role and how fieldwork is like a continuous performance where I, and those around me, shift roles and sensibilities depending on the situation.

A second way in which the fieldwork was impacted by a management of boundaries was in relation to what activities I could take part in. The mythic view of anthropological fieldwork is that one jets off to a far place to live in a village with a family for over a year and do all there is to do (van Maanen 2011). Conducting fieldwork in the England complicates this approach as it is less feasible to 'live with' a family for a year; such involvement is viewed by ethics committees as excessive and it does not fit with English views of the home as a private place where guests are invited for relatively short time periods. Moreover, married with my own residence within the geographical area, from a personal perspective living in another setting for a year was undesirable and impractical. Yet it is difficult to replicate the intimacy one gains through living with your informants, so for those involved in the longitudinal study I tried to visit them frequently and often would spend up to six hours with them, sometimes sharing meals and going shopping with them. The purpose of this was to attempt to move away from a formal exchange of the interview to a more informal mutual presence where I could gain insights into their daily life as a friend or family member might. Whilst this worked well in terms of rapport, there were still spaces of the home that were never visited, times (such as in the middle of the night) that I was not there, and therefore there are many aspects of their lives and experiences I did not have direct access to . Similarly, due to the cultural context of consent and privacy, people had the ability to decide what activities, such as accompanying them on clinical visits, they would allow. As such, certain elements that were deemed more 'private' remained as such.

This has implications for the kinds of findings and statements I can conclude from this study. I do not wish to assert that I know how it is to be at the 'end of life' or the intricate details of what caring for the dying looks like. Those seeking more practical solutions (such as suggestions to improve EOLC policy) to arise from this research may well be disappointed because of this. This is the last boundary I wish to discuss here: the divide between understanding and improving. Located within the wider remit of both health services research and anthropology, as a researcher and as a project I am torn between the two. What lies at the heart of this division is a focus on the kind of impact one can/should have, and this is something I discuss more in Chapter 8. The purpose for mentioning this here is that this presumed boundary obscures the more complicated issues of what doing fieldwork is like and assumes that impact can primarily be found once the 'data collection' has been completed. Rather than being a divide between disciplines, there is a schism between doing and using research and through the experience of fieldwork, which has often extended beyond the formal time periods set by ethics committees, lengths of PhD courses, etc. I wish to challenge this division and suggest that research is perhaps never 'done' completely as I and the people I conducted the research with, including long-term participants, continue to engage with the issues that arose from it.

All of these issues have implications for how the research was conducted and the 'findings' I can present and make sense of. I have demonstrated, where possible, how these experiences of doing fieldwork have raised similar themes to what was observed 'in the research'. Through this I illustrated how ethnography is therefore about experiential knowledge gained by the researcher by being there and doing the research. It is through

these experiences, as well as what is seen and heard, that one can make sense of the world

around them (Herdt 1988; Castandea 2006; Spencer 2011).

2.5: Conclusion

In this chapter, I have outlined the methodological aspects of this study, including the

approach and techniques employed through ethnographic fieldwork. Overall, this work is

based on a longitudinal study of choice and end-of-life care looking at policy, healthcare

practice, and people's experiences as they live with life-limiting conditions. Through an

ethnographic approach, I am able to relate choice and end-of-life care to the wider political

and social context, as well as open up discussions around discourse and how policy is

implemented into practice. Moreover, the level of engagement an ethnographic approach

affords enabled me to have access to people and subjects, which may otherwise be

considered too vulnerable, sensitive, or personal for other research methods. Yet, an

ethnographic approach is not only about the way fieldwork is conducted but how accounts

are made sense of and therefore throughout the remaining chapters, the descriptions are

woven with theoretical considerations, making sense of specific cases in relation to the

wider experience of living and dying in England.

During the discussions above, I have shown some of the encounters that shaped the way

the research was done and interpreted. Several key issues have been raised which I

continue to address in the following chapters. These include the practical implications of

categories and roles, learning through relationships and the importance of relationships,

and the potential impact of research into end-of-life care. By highlighting these themes

here, I wish to emphasise that they are not themes that are found 'in the data' but rather

ones lived through it, since part of the understanding gained through ethnography is based

on the experiences one has during fieldwork and the wider period of the project. In this way, rather than setting my data as an external other, there are times where I am embedded in the accounts I provide. It is through this notion of participation that the following chapters can be read, as I uncover categories, wrestle with how others interact with documents and each other, and reflect on what end of life may be like.

Clinical Shadowing

Late 2010

I've been out with several nurses now on home visits – seeing "patients" in their "own environments" ranging from the living room or conservatory, to the kitchen, to the bedroom. I hop in the nurses' cars and away we go covering the cities and countryside in between. Their car boots are full of paperwork – very little medication, if any.

With the district nurses there is usually a 'task' to be done, such as changing bandages or injecting insulin. Often during these moments, especially if they involve "more intimate body parts" I am sent to another room to look through the notes as "the task" is done. But with the specialist nurses, who go out and visit the kind of people I hope to be seeing as part of this research, we often just sit and chat with the patient. The nurse may have a pen and notebook out, a few pieces of paper grabbed from the car, but not much else. Unlike the district nurses, they are not in nurse uniforms. The only thing that marks them out from any other visitor is their NHS badge around their necks. I wear one, too, as if posing as a trainee nurse but they all know I'm not. My questions and silence are too naïve for that role.

After several tours with the specialist palliative care nurses, I'm surprised how "well" all the people seem to be that we are seeing. Perhaps they are censoring who I see, not inflicting death on me or a stranger on "their dying patient". When asked how they are, "well" is the answer. Maybe because that is the habitual way of replying to such questions. This wellness surprises me, especially in light of the conversations

that follow as I sit uncomfortably in their chairs. Couples tell of their depression and mutual fight with cancer. A woman comments how she is unsure if she can cope as her husband is bed-bound in the other room. But people nonetheless report being well.

And for me, the real surprise is how well these people physically look. I've never consciously seen a "dying body" but have witnessed family when they were unwell. Images of my grandfather in hospital, a bottle of white fat being pumped into his thin body and what looks like a morgue tag on his big toe spring to mind. [He lived for another ten years after this scene]. Lawton's (2000) book on messy dying is not

what I see or smell here. These people are at home, most of them up and moving, talking freely of how they are "getting on". Besides the stacks of medicine and the visits from the nurse, there is little evidence of their demise. I'm not sure what I was expecting, but this apparent normality is jarring.

Image 4: Albert with the sniffles on a cold day during one of our visits in a care home. With what clarity do I see him?

Part 2: Choice and English End-of-Life Care

Chapter 3: Defining End of Life, Dying and Dying Persons

3.1: Introduction: Contested Definitions and Mobilising Care

With a push to improve end-of-life care, what constitutes this phase of life – the end – is important to understand. However, what end of life is - or how it is defined - is not obvious as the term is used in various ways across policy, practice and in every-day conversation. For instance, it can refer to anything from the last hours to the last year of life (EIU 2010) and within English end-of-life care (EOLC) policy discourse it covers the last year of life, determined before death occurs (DH 2008). Clinicians acknowledge that it is often difficult to determine when this will be (Murray *et al.* 2005), and other words, such as terminal and palliative, are also used within these time frames. Understanding definitions is important as they shape practice and can serve as an impetus for change within the healthcare system (Kaasa 2001). The mirage of a boundary that marks the end of life relates to the difficulty of knowing what death and dying are and look like, and what to do about them. In this chapter, I outline how these different terms are defined within English health policy and practice, and the contexts in which they are used to illustrate the implications these categories have on relating to patients and death. The ultimate effect of defining 'end of life' as a distinct category that relates to a good death, as outlined in policy standards, is

that it constructs what a dying patient is and how they and their death should be managed within the health system.

  In this chapter, I discuss how the different categories and classifications used to define death and dying are informing new standards for evaluating and managing dying, and therefore relating to patients. To do this I draw on material from policy documents and observations of policy events,[25] clinical encounters, and discussions with informants to describe the various terms used. By using multiple kinds of data, it is possible to describe how death is talked about as well as acted upon and with, thereby illustrating the relations and relationality categories enable and are part of.

The first part of this chapter, describes how English EOLC policy engages with different notions of death to outline what it seeks to be a 'good death' as a new standard for how EOLC should be delivered and how death should be experienced. The following section continues with Foucauldian influences as I examine how categories of death – such as end of life – can be technologies. In this sense, how something (or someone) is classified has implications for how they are related to, including how they relate to themselves. Whilst this has been fruitfully described in the context of mental health (Scheff 1974; Socall and Holtgraves 1992), this chapter sheds light on how the categories of 'end of life' shapes who a particular patient set is and how they are related to by professionals, and how it is expected they will relate to themselves, their life and their death. Through the identification of 'end of life' patients are related through their bodies, and through the management of dying, are expected to be reflective individuals; as such, this is an extension of the medical

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[25] These included: regional EOLC strategy launch events aimed at health professionals and commissioners; national information days aimed as social care and health care workers; and all-party parliamentary group discussions. Audiences were often 100 people large and the events were in nice conference venues. The main focus was usually on presentations by selected policy makers with some time for limited questioning from the audience, giving them the overall purpose of "information events".

gaze. It is through identifying a person as being within 'end of life' that they become a patient of end-of-life care.

Later I illustrate the more nuanced ways multiple classifications and categories are used simultaneously and how the same term is employed in different manners. Bowker and Star (2000) note that although categories are ideally mutually exclusive to be meaningful and enable action, they are often a site of negotiation. This is evident in the discussion of 'terminal', which was used differently by professionals and patients, and how more emic[26] terms may allude to, but not directly confront, death. I consequently argue that through end-of-life care policy that seeks to make dying into something that can be managed by identifying end-of-life and encourage open communication about death, the ambiguities inherent in the dying process are obscured. By retaining dying as a medical process, people are treated as patients, identified through bodily changes and 'needs' as they near the end of their lives. Ultimately, defining end of life is not about identifying when death occurs per se but capturing dying in order to have an effect on the kind of death experienced. The definition and use of end of life – and related terms – is a way to manage dying by positioning the person as a patient anticipating physical decline, yet able to reflect and act upon their incoming death. By being able to determine dying and who the dying patient is, this opens up the possibility for 'choice' in end-of-life care, which is the topic of the next chapter.

3.2: Incorporating 'Good Death' into healthcare policy

The ambiguities around defining end of life relate to the uncertainties around defining death and dying. The two words – death and dying – are often used interchangeably

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[26] An emic term is one that is used by the research participants. See the glossary in Appendix 1.

referring both to processes and event (Lock 2002:198) and I have kept this indistinctness to reflect their shifting nature as observed in this research. This section describes how EOLC policy engages with different notions of death and dying to promote a particular view about what death and dying should be like – a specific version of 'good death' focused around awareness, advance care planning, and place of death. By doing so, policy creates certain expectations about what death and dying should be like, leading to dying becoming a manageable process, which is discussed further in the next section, with a 'good death' being the ultimate goal.

As noted in Chapter 1, different definitions of death and discussions of 'good death' have occurred within the social sciences and public debate more generally, rather than within medicine per se. Barbour (2011) has described the process through which medical practice and policy engages with and incorporates versions of social theory as 'sociolization'. This is seen as part of a larger project of adapting to social change. In the field of English EOLC, policy has incorporated and reformulated notions of good death and social death, redefining them to suit a medical model of care management. More historically, the modern hospice movement,[27] which is credited for highlighting the importance and possibility of good quality care for the dying (Seymour 2012) can be seen as a response to social critique about death being overly medicalised and sequestered within hospitals (Illich 1976, Connor 1998, see Clark 2002 for a discussion). It is also set against critiques of dying such as social death and isolation, unawareness and unsupported psychological transitions (Sudnow 1967, Glaser and Strauss 1968, Kübler-Ross 1969) by focusing on 'holistic care'. This focus on the psychological, social, physical and spiritual needs of the patient, emphasising that patients

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[27] The modern hospice movement refers to the growth of hospice and palliative care since the late 1960s after St. Christopher's Hospice was founded by Cicely Saunders in London. The notion of 'hospice' is older than this. See James and Field 1992 for a history.

can be supported through the transition to death (Saunders 2006), and is championed as a way of focusing on the dying person rather than just their body. Since the 1970s, hospice care has been recognised as specialist care for patients receiving symptom-related treatment rather than curative treatment, often related to cancer. It is from within this framework, and with this history, that English EOLC policy comes from - a focus on the dying person as a whole and the experience of death, and a response to social concerns about how dying is handled within society and the medical system.

English EOLC policy explicitly states that everyone should be able to have what it defines as a 'good death'. The importance of providing a good death is highlighted in its inclusion as background information of the condensed executive summary in the National End-of-Life Care Strategy (DH 2008). Whilst 'good death' has been heavily debated within academic and professional literature (e.g. Hart *et al.* 1998; Walter 2004; Kellehear 2007a), indicating the concept's contested and varied nature, within EOLC policy it is treated as a relatively unproblematic ideal and goal. Even if people's understandings vary, as stated at multiple policy events, it is something "we all" should strive for as "we care for the dying and die ourselves". In this way, how EOLC policy categorises and conceptualises death provides not only a moralising discourse, but an indication of how such ideals shape healthcare practice and experience.

Within the EOLC strategy, good death is understood to comprise of particular key elements. These are in turn what practitioners (as well as patients and carers) should be working towards – they are components that are part of the standards of good dying. In parentheses are the implicit implications within these elements, as understood within the larger context of policy documents and in policy events. The defining features include: being

treated as an individual, with dignity and respect (although these terms are not qualified

and may include notions of choice); being without pain or other symptoms (drawing from

hospice care); being in familiar surroundings (often understood as one's home); and being in

the company of close family and/or friends (not necessarily medical staff). From this

definition two elements are explicitly missing that appear elsewhere in policy – awareness

of dying and choice. Both of these underpin EOLC policy and are seen as key mobilisers for

enabling a good death by allowing the patient to foresee their mortality and express their

preferences for where they would like to die and what treatments they do not wish to

receive. This is where policy's understanding of individual variability comes in; however, this

individuality is set within the larger dying script. This type of death and dying, classified as

the revivalist approach (Walter 1994), is to be standard throughout England as a result of

EOLC strategy.[28]

  Incorporating 'good death' is not the only element of sociolization within EOLC policy. In

an attempt to reclaim and reform the way death is considered to be experienced by most,

based on research and highly publicised cases of poor care and calls for assisted dying, EOLC

policy positions its version of good death against other ways of categorising death and

interacting with dying persons. There are three main categories of deaths that come under

this response: deaths within hospital environments when patients are expected to be dying

anyway (i.e. dying from a 'chronic' and not acute condition); physician-assisted suicide and

euthanasia (classified as 'unnatural deaths'); and 'social death' understood as where the

patient is no longer treated as a person. Sudden deaths are considered to lay within the

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[28] What was considered a 'good death' varied in practice depending on who I spoke to and this finding is consistent with the literature (e.g. McNamara 2004). Having some form of control, either through advance care planning, pain relief, or choosing one's time of death was often mentioned and responses broadly corresponded with policy's conception although not all elements were required for interview participants to view a death as 'good'.

remit of other health policy, namely prevention rather than care and are therefore not an explicit part of EOLC policy. Whilst these kinds of deaths may seem quite distinct and disparate, the idea that EOLC policy is trying to avoid them is significant in understanding what the boundaries of EOL and EOLC are and how they are managed. In turn, this has implications for who can be considered a dying patient and how their death can be responded to.

Hospitals are where most deaths occurred within the UK since the mid-1970s, with an increase in home deaths occurring only after the release of the EOLCS although most deaths are still projected to occur within hospitals (Gomes and Higginson 2008; Gomes *et al.* 2012). Some of these deaths will occur after what is considered by policy makers as long admissions (more than eight days), whilst others may occur within 24 hours of admission, where patients are typically admitted 'out of hours', between 5pm to 9am. This latter group of deaths are frequently referred to as "deaths following inappropriate admission". [29] The underlying logic of this is that if death was expected, then it could have occurred elsewhere, such as in the home. In these cases, hospitals symbolise an inappropriate level of treatment (and use of limited resources) as no curative or relief treatment could be provided. For example, a report aimed at nurses noted that up to "40% of patients who died in hospital did not have medical needs that required them to be in an acute setting", describing this as "not only expensive" but as "inappropriate" and "preventable" (Fenton and Maher 2010:7). Moreover policy makers refer to the environment of 'the hospital' (as a generic institution rather than particular setting) as being depersonalised, too technocratic, and busy; these images are contrasted with death as being a quiet, natural, and serene process, which is

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[29] Note how this refers to death and patients. The person is separated from their passing through the use of statistics.

presumed to be impossible to obtain within the pale green curtains of the hospital ward. Therefore, EOLC policy attempted to reverse the sequestration of death (Illich 1976) by classifying particular hospital deaths as inappropriate. This has material consequences for how health services are designed and delivered with a shift in the setting of care provision.

   The alternative engaged with by policy is 'home death' – death within the patient's residence, including privately owned or rented properties, social and sheltered housing provided by the State, and care or nursing homes.[30] All of these understandings of 'home' are considered to be "in the community", that is spaces whose main purpose is not to provide medical care and treatment and alludes to a more socially-grounded and public setting.[31] This does not mean that people are to be without medical treatment or care; financial funds have been dedicated to increase medical and social care for those dying at home. As experienced by those who live in homes where such deaths occur, through the provision of EOLC and death within them, they may be transformed into quasi-medical settings with the introduction of equipment like hospital beds and visits from numerous clinicians and carers. The category of home is quite broad and in the context of promoting 'home death' represents a re-appropriation of space in an attempt to align the setting of death with the underlying values of a good death of dignity and being surrounded by family. The consequence of associating home deaths with good death is that people are encouraged to die, or support the dying, at home.

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[30] At first the term 'home' was taken quite literally within policy to mean people's houses, where they had lived for many years. Now, in order to reflect current demographic patterns and improve the rate of home deaths, 'home' is understood to be both people's own houses (or homes), sheltered accommodation, and care homes. It is not clear though if a person's death that occurs shortly after a move to a care home – perhaps after being in hospital – is counted as 'home'.

[31] This is similar to a shift in the delivery of mental health services in the United Kingdom under Thatcher's conservative government in the 1980s known as "care in the community" (see Walker 1997 for a discussion).

Hospices, as the metaphorical home of holistic care for the dying, are often a viewed as desired place of death by the general public in surveys (Gomes *et al.* 2011)[32] although they are not viewed by policy makers as a viable population-level solution to inappropriate hospital deaths. Within the NHS, hospices represent specialist treatment and care; they are expensive to operate and "too medically focused" to be suitable places for all deaths. In the hospices I visited, most of the beds were dedicated for symptom relief with patients expected to be discharged within a fortnight. A person coming in specifically to die was an exception, reserved for a select few, and such instances were subject to heated and lengthy discussions amongst the staff. Allowances were made for patients whose disease or condition[33] "demanded" specialist intervention that could best be provided by the hospice staff. The affective nature of space is therefore not the only element in the push for home deaths. The classifications of deaths as good or inappropriate are informed by understandings of disease and need as framed within the medical system. Whereas hospice has stood for 'best practice' in end-of-life care previously, ways of framing dying through space and need combined with economic considerations influence policy and practice decisions about the new accepted standards of quality of dying and end-of-life care.

In terms of setting standards, by promoting a particular version of good death, EOLC policy resists what is grouped as 'assisted dying', which can include any manner of procedures and classifications such as euthanasia, physician-assisted suicide, assisted-suicide, and assisted-dying, often itself alluded to as 'good death' (see Humphry 2005). The premise understood

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[32] Whilst the survey statistics utilised by policy makers indicated that about ¼ of the population would choose to die in a hospice (Higginson 2003), a survey by DEMOS indicated that less than 10% wanted to die in hospices as they viewed them as undesirable due to the connotations of death (Leadbeater and Garber 2010). A recent report by Wood and Salter (2013) indicate that the older a person is, the more likely they would prefer to die in a hospice and this preference increases with those who already have experience of hospice care.
[33] This could include their psychological or social situations.

by EOLC policy makers to underline these types of death is that they are unnatural – "death

is not allowed to take its course" as stated by several people in interviews and

observations– imposing an impractical power dynamic between doctors and patients (and

their bodies), and immoral as the sanctity of life is not preserved. Nonetheless, it is

recognised that these types of death, or those seeking them, are attempting to control

(their own) death and suffering. Therefore, rather than ignore these as issues, EOLC policy

re-frames them in the form of 'choice' and specialist care. By providing patients the means

to exercise autonomy about the kinds of treatment they receive, and by ensuring they have

access to treatments which are understood to alleviate pain and other symptoms of dying

(including psychological ones, referring back to the holistic care model), EOLC policy aims

achieve the objectives of assisted-dying – control – without resorting to the methods its

proposes. For some EOLC policy makers, calls for assisted-dying only strengthen their

perception of the need for "good end-of-life care" as they see it. The naturalness, given the

kinds of medications and interventions used, or moral nature of their version of good death

is not questioned. Instead, a death supported by holistic care has become the ideal standard

to which other kinds of dying are contrasted against.

Lastly, social death is another category engaged with by EOLC policy in that policy makers

sought to address the apparent lack of dignity and respect for elderly and dying patients.[34]

The solution proposed is "person-centred care" within an "open and honest environment"

that discusses death. Dying is therefore to be about the person, and what they want, within

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[34] Care of such patient groups is routinely scrutinised in the public press (see Butler and Drakeford 2005 for examples) and policy makers will hold up such case studies, remarking "we're not doing a good enough job". During the course of this research, in the popular press and media deficits in care were attributed to various factors, including: the elderly generally not being respected within society; death being a taboo and therefore avoided; and too few staff and too little time for relational care in various settings. The culmination of these is that patients are ignored at a time when, as posited by policy makers, they need to be supported and surrounded by those 'close' to them.

a community that acknowledges death. This is where 'choice' and advance care planning comes to the fore. By involving people in decisions, and planning for, their death, they are to be 'persons' until they die and in their death. Respecting choice is seen then, by policy makers, to equate to respecting the person, and that previous ways of caring for the dying lacked this "dignity" and personhood. Dignity and respect are enabled through choice, as presumed by policy, by asserting the agency and autonomy of the individual. Additionally, when death is seen as something to be anticipated and talked about – for how else is the patient involved in decision-making if death is not talked about – according to the logic of EOLC policy, people are less likely to experience social exclusion before they physically die. However, since death is posited as a "taboo" (DH 2008:37) and therefore not talked about, efforts are made to encourage the public to engage with death and dying, and to talk about it even outside clinical encounters as illustrated the by public policy campaign "Dying Matters". Remaking death into something that is discussed and focused on the individual is therefore an attempt to avoid the lack of dignity and respect observed with care settings. Through this, a particular kind of dying person, social community, and dying are constructed.

Good death as interpreted within policy is therefore more nuanced than the explicit definition. The focus is on the individual and the context of their dying, providing them a certain extent of 'choice' about what this may be like. There is an assumption that people want the kind of dying outlined within policy. By avoiding hospitalisation, deaths should occur within private spaces where invasive technological treatments are relatively absent but medication and supportive equipment can be present. 'Choice' however is not a blank-cheque for determining the moment of death when control over dying is still largely within

the realm of the medical profession who can provide support, through for example pain relief, and 'nature', which determines the rate and time of "ultimate decline". By defining the boundaries of good death through the terms of social debate and theory, such as social death, EOLC policy sets a standard of dying that locates it within a modern secular context concerned with control and individualism (Seale 1998).

I would argue therefore that through such policy and constructions of what makes a death good, death is still medicalised even if overly technological approaches and places are shunned for a more 'natural' portrayal where patients have choice. The process of sociolization does not negate medicalisation but is part of it. This is because how dying is determined – and managed – is within the realm of the medical profession, and importantly, they are the institution determining what a good death looks like. This form of medicalised death is one where the dying process is to be managed with the individual patient in focus, in order to bring about a new form of good death. What underpins this form of death is an imperative, particularly for the medical professional and the patient, to provide opportunities and plan and make choices for this kind of good death to occur. How advance care planning is done is discussed in the next two chapters. Taking the idea forward that good death is a foreseeable and planned death, the next section explores how end of life is to be identified and therefore death and dying managed according to English EOLC policy.

3.3: Managing and Defining the Dying Process

Good deaths are what healthcare policy aims for in the absence of a cure – or avoidance – of death. It has become a standard outcome by which services, care and lives can be measured. In the previous section, I described how EOLC policy's focus on good death

represents an engagement with social theory and debate, incorporating these concerns into clinical practice. In this section, I describe how this is done through identifying the phase designated as 'end of life' and the use of the end-of-life care pathway as launched by the Department of Health in 2008. Acknowledged as the first of its kind (EIU 2010), the pathway and the policy in which it is embedded construct dying as a recognisable and manageable phase linked to understanding dying as a trajectory. If this linear decline is correctly identified and the process of such dying managed according to the EOLC pathway, good deaths are considered by policy to be the ultimate and logical result. It is within this framework, however, that the focus shifts from dying persons to dying patient as people are subjected to medical understandings of life, death and care.

  Although the EOLC strategy does not explicitly apply a time-frame to the category of end of life, during policy events related to the strategy it was often understood as the last year of life. This interpretation of the strategy into a figure represents how policy is operationalized within the system – the category of end of life is defined in order to make use of it practically. Prior to a focus on EOLC, health professionals rarely predicted death with much certainty unless a patient was 'on death's door', or what is now referred to as active dying (Bishop 2011). More diffusely, in interviews and informal medical literature, there was a sense that fate, the body, or some other force beside the medical professional could decide when the life was over. Relative risk of death could be 'gu-estimated'[35] through years of professional experience and statistical compilations of similar patients, yet developments in medical technology continued to push the boundary of death by enabling people to 'live'

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[35] This is a combination of guessing (based on personal experience and the current situation) and estimating (based on epidemiological research). This act was alluded to by several healthcare professionals in interviews about how they determine when a patient may be 'end of life'. It is less mathematical than notions of relative risk imply.

beyond otherwise liveable states (Kaufman 2005). The way health professionals relate to death has changed through developments in knowledge and technologies, and death is no longer unknowable, or out of clinical control, but redefined and related to through medical science and care practices. As Christakis (2001:24) states: "the notion that death can and should be accurately predicted is especially consistent with broader contemporary beliefs about the possibility of managing death". The remaking of death, through technology and changes in definitions, enables death and dying to be an object of clinical management.

Rather than define notions of biological death, EOLC policy seeks to predict and anticipate death and dying when they would otherwise not be formally identified so far in advance of their occurrence. After the launch of the national strategy, it was openly acknowledged in meetings that there were little clinical criteria for prognosticating death in most patients a year out from death. Instead, healthcare professionals were to rely on their intuition and practical knowledge of patients, by asking themselves "would I be surprised if this patient were to die within the next 12 months?".[36] This 'surprise question' forms the basis of deciding whether a patient is 'end of life'; if not surprised, the patient should be considered for the EOLC pathway and advance care planning (ACP). This relies on different forms of knowledge – intuition and practice –rather than scientific or bodily evidence to formulate the decision. EOLC policy is different to other areas of health policy that emphasise evidence-based medicine and clinical outcomes. The basis for classification and action within EOLC is therefore allowed to be a different form of recognised medical knowledge, albeit often characteristic of an older model of practicing medicine (e.g. Helman 2006).

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[36] The surprise question was not invented by English EOLC policy but was drawn from research literature on dying (e.g. Johnson *et al.* 2003, Lynn 2005) and popularised in the UK by the Gold Standards Framework (GSF) prior to the EOLC strategy.

The question and pathway initiation has been heavily aimed at general practitioners (GPs), district nurses, and care homes with the presumption that these service providers know their patients well due to a higher frequently of contact over a longer period of time. Whilst these expectations may not always be appropriate (e.g. patients may not always see the same GP) it assumes that these people can readily see and recognise decline in the persons in front of them. This is relational knowledge. Given the presumed importance of rapport with patients for "end of life conversations", this relational knowledge is also considered to enable better conversations. Not only then are GPs, for example, able to recognise decline, they are also best placed, because of their knowledge of the patient, to tell them they are 'end of life'. Since the goal of EOLC is a good death, that involves planning for the death rather than recovery, there is less of an emphasis on medical interventions to change the body. Instead the quality of relationship between the dying person, their body, and the health service is important.

In my observations, the surprise question rarely lead to definitive conclusions about a patient's health status. Comments included: "I never thought about that…", to "they could have been a few months ago, but now I wouldn't say so", to "they could be, but it is so hard to say…". One specialist nurse responded to a patient's question about prognosis with "how long is a piece of string?" before proceeding to talk about disease-related dying trajectories. Dying trajectories are a clinical way of explaining the pattern and rate of decline for patients as they reach the end of life; their emphasis on observing the body makes them clinical. The notion of dying trajectories originates from social theory – Glaser and Strauss first discussed them in the 1960s to describe processes of care in hospitals (1965, 1968) and Kübler-Ross (1969) model of grief also gives the impression of change over time. The incorporation of

trajectories into policy is an example of sociolization. For clinicians, the trajectories correspond to different rhythms of decline and can provide indicators to the focus of care and treatment. Whilst an individual patient's exact trajectory may differ from the norm, there are three accepted forms of trajectory that broadly map on to different disease and decline-type categories, excluding 'sudden deaths' that result from accidents or "unexpected acute events" as these cannot be anticipated. Even though the trajectories are 'agreed', the clinical usefulness of these trajectories is debated (e.g. Gott *et al.* 2007). The trajectories map bodily function along time, illustrating a decline in function with time (see Image 5). Within the images, although both time and function are used as scales, no units are provided. Their meaning comes only from relation to one another and there is no universal time or function to compare – or map – a patient onto these trajectories. In this way, dying and who 'the dying patient' is remain relatively abstract until clinicians recognise these patterns in the bodies they encounter and the notes they read.

Each trajectory matches the clinically expected pattern of dying from different kinds of conditions – "how a disease will run its course". The trajectory with the short period of evident and rapid decline represents death from "terminal illness", often cancer (Noble *et al.* 2010). The second trajectory shows a generally lower level of function, during which decline is interspersed with sudden dips labelled as "exacerbations" which frequently result in hospitalisation; this is considered typical of organ failure following a longer period of chronic illness. The third trajectory depicts a slower, gradual rate of decline and has been linked to those labelled "frail" or "frail elderly" who are experiencing "prolonged dwindling", with "general frailty of multiple body systems" (Lynn and Adamson 2003:9). This trajectory is considered typical for those with neurological conditions, including dementia

and Parkinson's disease, disabling stroke, and 'old age'. Here old age – and even general

frailty – is referred to in the same way as medical conditions rather than stages of life

although this trajectory is sometimes viewed as "natural" (Noble *et al.* 2010). Overall, the

trajectories are used to identify the patterns and progress of likely decline and to categorise

patients on these means.

Number of deaths in each trajectory, out of the average
20 deaths each year per UK general practice list of 2000
patients

—— Cancer (n=5)
--- Organ failure (n=6)
----- Physical and cognitive frailty (n=7)
Other (n=2)
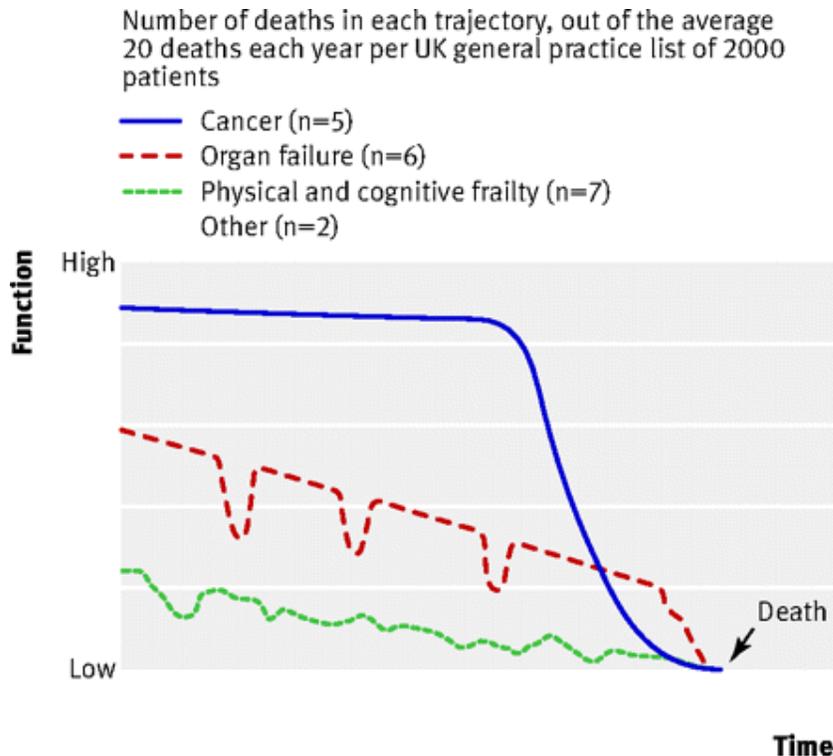
Image 5: Dying Trajectories with relative rates of death per each on average in the UK. Image from
Murray (2008) which is adapted from Lynn and Adamson (2003). Lynn and Adamson (2003) estimate
that 1/5 of deaths match the cancer trajectory, 1/5 correspond to pattern identified as organ failure,
and 2/5 due to frailty (the other 1/5 relates to sudden deaths).

   Moreover, the trajectories are viewed to correspond with and prompt practitioners to

think about the kinds of "needs and care" patients may require. For example, patients who

are identified as matching the first trajectory are suggested to receive specialist palliative

care (Lynn and Adamson 2003) whilst patients who experience exacerbations are taught to

self-manage and self-medicate – such as being given an "emergency set of medication to

avoid [pulling] the [emergency] cord" as one interviewee referred to it. Yet, the high level of unpredictability in the second and third trajectory about when and how death might occur means healthcare professionals must manage this uncertainty, both for themselves and their patients. For example, many doctors I spoke to were unsure of when to begin EOLC conversations with patients who could be experiencing the decline typical of the third trajectory as they did not wish to cause undue distress if the patient continued to live for many years; although patients fitting this category were expected to die, knowing when to implement the EOLC pathway was viewed as problematic. Instead they sought to identify when transitions in care were needed, typically occurring after hospitalisation, and to support carers. For all three trajectories, by identifying the likely pattern of decline that a patient may experience, it is expected that healthcare professionals will be able to anticipate that decline and respond accordingly in terms of the care they provide.

Although time is left unstated within the model, some authors and clinicians have sought to apply time frames to aid prognostication. For example, with the first trajectory there is a noted steady decline one to two months prior to death (Teno *et al*. 2001; Lunney *et al.* 2003; Costantini *et al.* 2008). In this way, death is foreseeable and to some extent dying is time-limited and this time is knowable; therefore dying patients can be identified and dying can be tracked and planned for. For the second trajectory, death typically occurs during one of these exacerbations; consequently death is viewed as relatively unpredictable although perhaps expected provided the overall decline. Similarly, in the third model, slow progression can lead to difficulties identifying when death is near. In interviews, doctors referred to patients that fit this category but could go on living for years. When considered as 'end of life', their placement in this category extends the time period it refers to, thereby

complicating prognostication.[37] Consequently, the EOLC pathway is viewed by many, as

often expressed in policy events, to be modelled on the first trajectory as this is the one

with the most predictable decline; however, most people are likely to suffer from conditions

that do not readily fit this pattern and therefore, whilst overall decline is expected to be

noticeable, timing of death is more uncertain.

Reflecting back on the nurse who alluded to dying trajectories to comment on prognosis,

by using the chronic decline model she conveyed information about the process of dying

whilst highlighting the uncertainty about the timing of the event/death. This provided her

with a justification for her initial answer about the difficulty of prognostication in death and

dying. When death is difficult to predict, the evasiveness of the models and the surprise

question allow death to be discussed and anticipated even if not pinned-down. Therefore

whilst the trajectories or surprise question may not be diagnostically helpful, or always

agreed upon, they allow people to convey particular messages in the presence of

uncertainty and disagreement.[38]

There have nevertheless been attempts to devise more precise clinical markers of dying as

an extension of evidence-based medicine.[39] It was in one GP's office that I was introduced

to the refined 'surprised question'; a response to doctors complaining how difficult it is to

diagnose dying – that is to identify that a patient may be declining as the trajectories imply.

This is important since diagnosis is the main process through which medicine makes sense

of, and gives order to the world (Jutel and Nettleton 2011). The doctor pulled out a sheet of

paper to be used as a diagnostic tool with the surprise question at the top, and below were

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[37] Although some doctors speculated in interviews that admission to a care home generally signified a higher chance of impending death within the next six months to a year for patients.

[38] This is similar to Young's (1995) observation that clinicians may not agree with the categories they use but find them practical for communicating with other clinicians and recording their activity.

[39] See Grayson (1997) for an overview of what evidence-based medicine is.

four categories of physical changes and/or markers that could be tested.[40] His task then

when considering patients that could be a 'maybe', was to see if and how patients fit into

these different clinical markers and then treat them based on the results. Scoring patients in

this way is akin to assessing their relative risk of developing a disease (see Rapp 2000;

Armstrong and Eborall 2012). Although death is to be considered as something inevitable,

this process turns it more into probability than a certainty – something to only consider if it

is more likely than not to happen. This particular doctor was in favour of this additional

diagnostic tool as he felt it would help GPs identify the 1% of their patients likely to die

within the year.[41] This, however, in effect turns something that was grounded on relational

knowledge into something based on abstract, statistical numerical figures and tests.

Moreover, it transforms the patient as relational subject and person with whom the doctor

interacts to an object (a body) that can be treated.

  Whilst these transformations may seem stark and antithetical to EOLC policy, which is

'person-centred', it is only through the process of identification as 'end of life' that a person

– as a patient – can be the object of EOLC. Therefore in order to treat them as a subject that

can choose and be aware of their death, patients must first be viewed as objects through

their declining bodily functions. This transformation is not as immediately evident as it

sounds. For the professionals I spoke to, it was often a gradual realisation about patients

that they could be categorised as 'end of life' and therefore treated differently. Often, they

reported, this thinking happened in the absence of the patient – after a consultation or in

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[40] This was a version of the Supportive and Palliative Care Indicators Tools (SPICT) which can be seen in Appendix 5.
[41] The 1% campaign was part of the National End-of-Life Care Programme's annual message in 2011 to encourage GPs to think about EOLC with respect to their patients and to view it as part of their job. The 1% figure is taken as an average based on the rate of death in the UK per capita. Such an approach to GP practice, where they are presented with an abstract statistic and asked to apply it to their 'patient load' is not unusual within the NHS.

discussion with someone else about other patients. When shadowing one GP, over lunch I

asked her about a man who had come in earlier, someone who had described relative

decline. It was only after our conversation that she considered flagging up end of life

questions in his notes, not as he was in the room with her. Consultations are spent on trying

to "problem solve what is in front of you" and categorising someone as 'end of life' does not

fit within this interaction; instead, thinking about a person's long-term health required

"reflection" that many doctors felt they could not do during short visits with patients.

Becoming 'end of life' is therefore a process over time, much like the trajectories indicate. It

is not a split moment in a consultation where all of sudden they are transformed from being

generally unwell to dying, but a slow realisation, on the professionals' part, that this person

may no longer be as well or likely to be as well as previously anticipated. This is the invisible

start of the EOLC pathway, so gradual it can be missed. It is in this transition that a person

shifts from being one kind of patient to another.

  The National English EOLC pathway (Image 6; Image 7 is a regional adaptation) consists of

six steps and four support/care elements that should span all steps. Pathways are a

contemporary way of structuring and modelling care more widely within the NHS and

provide a set of guidelines for professionals. The model is to be used by practitioners and

commissioners to design services in order to deliver 'good' EOLC – this is the standard

against which services are to be evaluated. Emphasis is placed on *awareness* of dying and

planning for dying. Each step describes a stage or process that is to be acted upon in order

to ensure a good death. There is a sense that there are key moments when certain actions

should occur or when certain moments of dying can be recognised without being specifically

defined. In this way, 'end of life' takes on a linear sense of decline where each phase of

dying can be anticipated and managed; this linear approach to dying reflects the trajectories upon which the pathway is modelled. The representation of EOLC as a pathway implies that dying can be reduced to an incremental step-by-step process, and thereby the management (in lieu of active treatment) can similarly be reduced down to tasks. However, the steps described are sometimes phases, process, or services; whilst the pictorial image implies simplicity, the inconsistent descriptions hint at the complexity of care services and dying. Similarly, how the transitions are made between the steps is unclear. This mismatch is an artefact of the health policy making process in England where theoretical unity is imposed on a disjoined system, as there is often little communication between sectors of the system including a lack of patient note transfers. Nonetheless, the momentum implied by the rhetoric and imagery of a pathway suggests a linear process with incremental steps along the way, and that death is ultimately foreseeable and therefore something can be done about it to affect the kind of death experienced.

If all steps are followed, the goal - a good death shall be reached; although this is not explicitly stated in the figure it was often mentioned at policy events and in interviews about the outcome of the pathway. In this way, the pathway adds further layers to what constitutes a good death from a policy and service standpoint. Here coordinated care, communication, and continuous planning and anticipation of future 'need' are essential elements of a good dying process. Moreover, a good death does not end at the moment of death but continues post-mortem in the treatment of the body and the bereaved. Managing the dying process is about positing care services to oversee and anticipate what will happen next, managing both the body and the people involved.
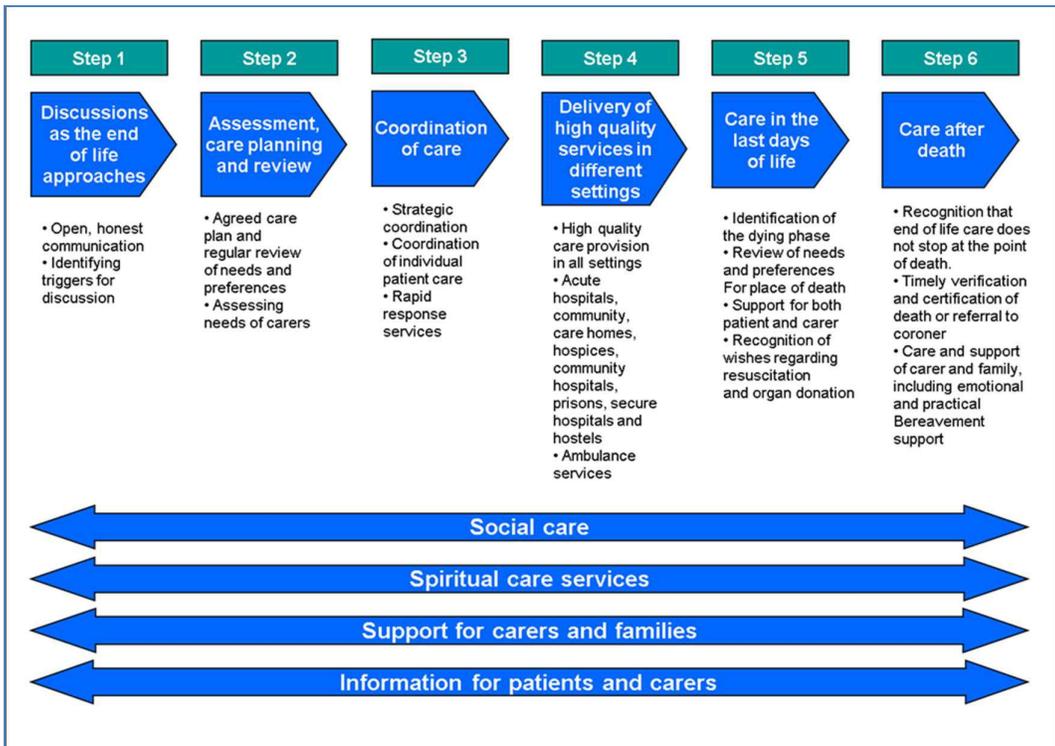
Image 6: National End-of-Life Care Pathway (DH 2008)
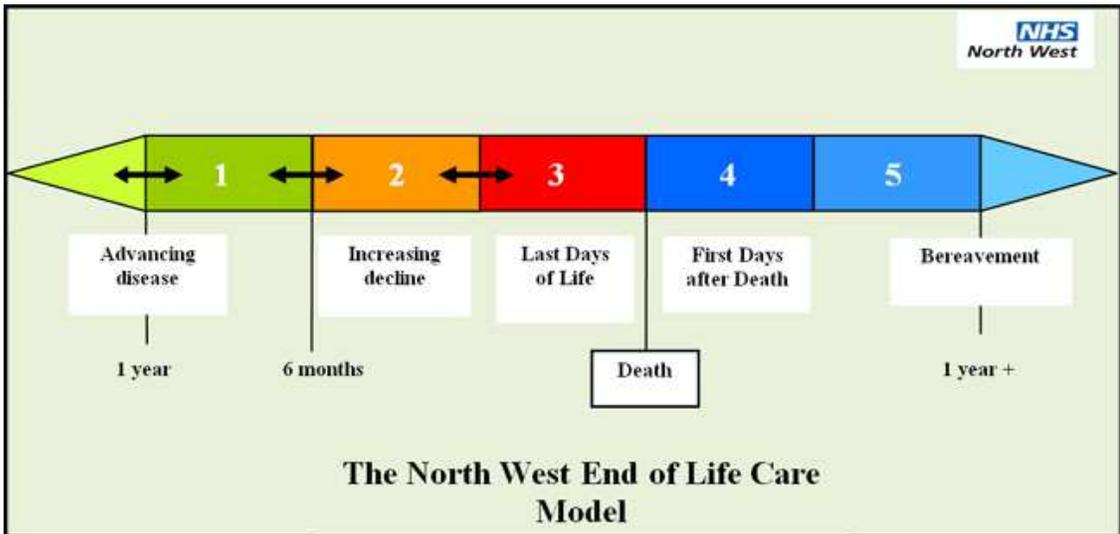
Image 7: Regional adaptation of national end-of-life care pathway (NHS North West 2010). Multi-directionality of arrows may imply a more fluid concept of time and progression. Regional adaptations represent the mobility and fluidity of national standards, whilst still emphasising their utility in creating uniform practice and ideals.

Interestingly, how one enters this pathway, or is "put onto" this pathway (as frequently spoken of), is not clear from the way the pathway is represented pictorially. At several policy and promotional events this has been highlighted as 'step 0', a phase that happens before the rest of these can even begin to be considered. The individual patient is relatively absent in this imagery. Only those who are categorised as 'end of life' are addressed by the model and considered to be 'dying'. As discussed earlier, such identification is presumed possible and here it is deemed necessary for good EOLC. This is because the EOLC pathway is a model for mapping care onto agreed dying trajectories. Nonetheless, failing to recognise a patient as dying implies that they would not receive this standard of care. Recognition and anticipation of dying therefore has direct implications for the clinical treatment of patients.

Being able to identify a patient's likely trajectory through clinical diagnosis and place on a trajectory through knowledge of clinical markers of bodily functioning over time has two main uses for a clinician. The first is that death can become more knowable or at least acknowledgeable, and in some cases, time to death may become estimable. Secondly, the type and place on a trajectory is considered to correspond to certain care needs. Thirdly, although the EOLC pathway was modelled off the first trajectory, being able to apply the linear vision to other patients serves to demonstrate performing clinical 'best practice' by aligning with current policy. The trajectories and EOLC pathway therefore mean something for care provision and expectations about what people – health professionals and patients – are to do. In this way, the classification of 'end of life' and matching patients' physical characteristics to dying trajectories has material, practical and professional implications.

The trajectories and by implication the EOLC pathway are therefore considered relatively universal and applicable to different deaths, often irrespective of exact condition or age.

The end-of-life care pathway can be viewed as a technology in the sense that it creates certain practices for categorising and responding to dying. Through the trajectories patients and their future deaths are known through their bodies. The purpose of identify dying is to be able to manage the process. By focusing on managing the process of dying, the event of death is also implicitly subject to this management. Moreover, the dying patient, as a subject and embodiment of dying is to be managed. This has implications for how patients are related to; in the context of dying using these frameworks, clinicians are placed as knowledgeable about when and how to identify dying and the patient's and their dying bodies are to be managed through the process. These models represent something that a person is placed into or mapped onto, rather than an expression of their individualised journey towards death. Their clinical use theoretically comes from their universality, although clinicians have expressed difficulty applying them to particular patients in situ given the lack of units.

The emphasis on decline presumes an overall unilateral downward movement of bodily function over time. The focus on the body as a way of foreseeing death – and in some cases cognitive function as measurable by biomedical tests – does not allow for other ideas of dying such as framing it as a social process, (Kellehear 2009), a time of identity transformation (Sandstrom 2003) or spiritual progression (Rinpoche 1992; Murray *et al.* 2007). The idea of decline implies a one-way track with no return, eventually leading to death. In this way, death becomes knowable and manageable through the ability to map functioning over time to enable predictability, even in the cases of 'sudden death' as a result of exacerbation since this is part of an overall pattern rather than a complete anomaly. Nonetheless the trajectories still leave 'end of life' and 'dying' undefined even if they are

indicative of these through the notion of foreseeable and traceable decline prior/leading to

death, which questions the usefulness of such distinctions in terms of improving care for the

dying , the very subject they seek to address. Through the use of the EOLC pathway, a

particular view of dying can be responded to and managed through a set of tasks and

processes, even if death and dying more broadly are left relatively undefined in these

models. The next section explores how concepts related to 'end of life' are used within

policy and practice, and the different ways in which they make patients knowable subjects

of different aspects of clinical care.

3.4: Categories of End of Life and Dying

In the English EOLC policy context, 'end of life' is defined as the last 12 months of someone's

life, which is to be identified pre-mortem – that is before someone has died. In effect,

healthcare professionals are asked to predict whether or not their patient will die within the

next year. This section outlines the various definitions used within healthcare policy and

practice to outline dying under the wider umbrella term of 'end of life'; each of these

categories impacts the way people are related to and how care is framed. Importantly,

rather than being discrete categories, there is considerable overlap and the time-frame to

which they can apply often extends beyond the last year of life.

Many of the people I spoke to, especially those who were not healthcare professionals

working within EOLC, did not expect to be considered 'end of life' months before they were

dead. This long period was considered "arbitrary", "strange", and "damning" by some;

others joked that "we are all dying since birth". A few told me quite frankly that "I am not

there yet" and that this was something to be considered in the future but not now. What

these comments illustrate is the apparent arbitrariness of the 'end of life' definition as used

within policy discourse in relation to what people felt, and knew, about themselves. 'End of life', as defined as the last year of life, was therefore a foreign concept for them and not one they used to refer to themselves. The transition to being a dying patient was not mirrored in how people related to themselves. Instead, end of life as a way to refer to a person was viewed as a concept applied to a person – as a patient – rather than a self-defined period of time that reflects one's embodied experience. Importantly, it positioned clinicians as identifiers of this phase even if it is deemed to be located within the patient's body and life course.

There was one exception to this directionality, and it came about when someone had to make a decision about life-prolonging treatment. This example from my fieldwork illustrates how the categorisation of patients as 'end of life' is unstable and contentious. Eva had renal failure[42] and doctors informed her that without commencing frequent dialysis soon she would die within the next year; effectively without treatment she would automatically be considered 'end of life'. When we first talked she had decided against dialysis; however, a few weeks later she had the pre-dialysis implant operations. When I asked her about this change, she confessed that she felt she had more than a year's life "in her" and dialysis allowed her to change her life span. Being in 'end of life', as she would have been classified, was therefore something she actively resisted by opting for treatment. This is similar to what Kaufman (2005) describes in America; however, this decision, of becoming EOL or not, was unusual in my research and the emphasis on prolonging treatment is not as prevalent in the UK as it is in the USA primarily due to different approaches to active treatment and palliative care. Nonetheless, this example shows that a patient can play an active role in

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[42] Renal failure is a condition that affects the ability of the kidney's to process waste within the body. Left untreated a person's health will deteriorate as toxins build up in the body and this is considered fatal.

their classification as 'end of life'; patients are not passive recipients of labels but interact with medicine and the professionals to forge and establish their presence.

As noted earlier, the definition of 'end of life' as the last 12 months of life is a relatively new convention and as such, EOLC is generally viewed as an extension or enhancement of palliative care of terminal patients (Seymour 2012). Sometimes these terms are used interchangeably; however, what and who is considered palliative or terminal does not always overlap with end of life. When shadowing nurses, both in the community and in the hospital, it became apparent that other phrases were used in place of 'end-of-life' to refer to patients that were in varying degrees of 'dying'. These terms – and how they were used – seemed to vary from setting to setting, team to team, but can be broken down into three main categories: palliative, terminal, and 'active dying'. Moreover, specialists of palliative medicine and care may have a stake in reinforcing the differences, especially as EOLC is aimed at generalists – spanning all medical sectors and settings – and care services. It is important to note that these terms were used in a particular way within the nursing teams, to refer to patients needing specific kinds of treatment and care, and did not always correspond to how patients referred to themselves. The following descriptions outline these categories and how they related to patient care and interaction, demonstrating how dying patients are conceived of and classified based on their physical needs as considered characteristic of symptoms of decline and dying. The categories are therefore indicative of different forms of patienthood.

Understanding the nuanced use of palliative is best illustrated from a conversation I had with a consultant, who worked in hospitals, hospices, and the community. She quickly corrected me one day that she was a consultant of palliative *medicine* and not palliative

care.[43] The former, which she likened to the founding practices of the modern hospice movement, is concerned with specialist treatment of patients' symptoms when the ultimate underlying cause, such as cancer, cannot be cured. The use of this specialist knowledge often comes at a time when other clinicians' recommendations or knowledge is ineffective. The prime example, she said, was in the administration of opioid-based pain relief. The dosage, frequency, and rate of increase, as well as contradictions with other medications and side effects, are things she classified as the specialist knowledge of palliative medicine. Due to the focus on symptoms and medical treatment, this is its own clinical field and primarily the realm of doctors.

Palliative care, on the other hand, was described as less specific and more diffuse in the relationship between patient and care-giver. The main goal is described as "primary comfort when we can do nothing else", but may also include helping patients to cope with their condition and mortality. Not all patients who may need or qualify for palliative care would require palliative medicine. Moreover, it is likely that patients will see other healthcare professionals, such as nurses, physiotherapists, and occupational therapists. From a clinical perspective, what palliative care is and who performs it differs from palliative medicine.

Palliative care and medicine are therefore two ways of describing what and who interacts with a patient who is no longer, overall, in receipt of medical intervention aimed at curing or reversing a condition. However, unlike in America where the transition from acute treatment to palliative is clearly marked, in the UK this can be a more gradual, particularly in hospitals, and patients frequently receive curative treatment for secondary conditions, such

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[43] The difference in terms represents conflicts amongst practitioners about the field (Billings 1998) and this distinction can even be found in academic journals based on titles. Palliative medicine became an accredited speciality in the United Kingdom in 1987 (Ahmedzai 1993). There are multiple definitions of palliative care (Pastrana *et al*. 2008), although in many definitions palliative medicine is a part of palliative care (Cairns 2001), and a key element is the irreversible nature of the disease (van Mechelen *et al.* 2013).

as infections. Nonetheless, there is a sense that when deemed a "palliative patient", a patient receiving either palliative care or medicine, they receive different kinds of treatment, attention, and care. A patient's label is provided by and reflects the treatment they are subject to.

When shadowing district nurses, I was shown the list of patients to be visited through the week. Some of these patients had palliative as a marker next to their name. "This means we are to focus on comfort" one nurse reported. Another said this further indicated that they might need to spend more time with the patient on their visit and that it might not just be a "task-based visit". They were also more likely to visit a patient over the weekend if palliative was next to their name. Consequently such patients received "special treatment" and palliative care was seen as a particular and different part of the job, with dedicated binders on the shelves in the office. When I asked if this meant these patients were 'end of life' I was told that the two terms are not entirely correlated. "Someone can be palliative but not end-of-life – they can live years like this". The second nurse added though, that this term indicated they should think about end of life if necessary and be ready to be planning for changes, especially if decline could be sudden. The examples they provided tended to be of patients with cancer, no longer receiving treatment to eradicate the disease, but also not "in the clear", often suffering from pain or other related symptoms that required regular monitoring. Unlike most of their other patients who had diabetes and needed regular visits for insulin and wound care, the tasks related to palliative patients could be quite varied and required extra notes. In this sense the term palliative next to a patient's name represented a particular way of seeing and treating, that a patient was significant enough to require this marker in all the notes.

Use of such signifiers is not new within medical settings.[44] One symbol used towards the end-of-life reportedly embraced by patients is the use and labelling of the Gold Standard Framework (GSF). I did not come across regular use or reference to this in my fieldwork; this account is from a promotional talk about the framework at an international conference on advance care planning (ACP). Like other EOLC tools, GSF is aimed at ACP and facilitating co-ordinated care centred on patient choice. In places where the tool is frequently used, patient records and names receive a gold star or sunflower to denote that they are part of the framework, and therefore those caring for them should pay particular attention to their notes and previous stated wishes. It was boasted that some patients even have a card in their wallets declaring that they are a "gold star patient" which they proudly produce whenever admitted to hospital, presumably as this improves (the experience of) their care. What this example demonstrates is how a label – which refers to the type of care a patient should be receiving – can simultaneously refer to patients and used by them to mobilise care. Labels therefore not only change how professionals interact with patients but also the experience of that care when the label is used to facilitate particular materials and actions.

Another category used by the community nurses I visited was "terminal", which referred to patients who were likely to die within the next few weeks or even days. They had at least one patient per week with this status and they were to be visited "more frequently and on the weekends without question". Such patients could have any disease, but their condition was understood to not only be irreversible (as is for the palliative patient) but also directly related to their death, which was considered imminent. When asked how they could tell if a patient was 'terminal', some said "you just know" whilst others said "when the doctor says so". They were less concerned about the acquisition of the label and more focused on the

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[44] For example, Timmermans (1999) and Beach and Morris (2002) with reference to do-not-resuscitate forms.

frequency and kind of care required, which necessitated special training. This category

denoted that both the person, and the condition, is terminal, and by extension the care to

be provided.

The phrase 'terminal' is quite similar to the term "active dying" used within the hospital

and a particular feature of the Liverpool Care Pathway (LCP). Patients who are considered to

be 'actively dying' are ones who are likely to die within the week, usually within 72 hours. It

is the process of dying rather than the event of death that is being alluded to in the term,

although death is implied. Unlike the difficulty with identifying 'end of life' 12 months prior

to death, active dying is considered by healthcare professionals to be more "visible" and

therefore recognisable, although specific criteria are not provided within the framework for

diagnosing dying. When identified as 'actively dying' tools like the LCP encourage the

removal of non-symptomatic relief drugs, nutrition and hydration as these are considered to

complicate the natural, biological, dying process (Seymour 1999, Freemantle and Seymour

2012).Within the hospitals I visited, patients on the LCP were often given a private room to

allow visitation and a "more peaceful death", or if possible, quickly discharged home. In the

community, "LCP patients" similar to "terminal patients" received more frequent and

lengthy home visits and potentially received home visits from general practitioners to avoid

a post-mortem.[45] Although generally considered to be a linear process, some patients may

recover from such scenarios and go on to live on after this period. This is what lies behind

recent negative media attention around the LCP in that it may be seen as a way of forcing

death on patients as treatments are withdrawn and/or withheld.[46] It is this period, however,

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[45] Legally a doctor can only certify a death if they had seen the patient within the last fortnight before death,
otherwise an autopsy is required.
[46] There were numerous accounts and cases discussed in the English public media during 2012 and 2013,
which lead to a review of the use of the LCP that was underway at the time of writing. Examples include the

that most people, especially non-professionals, think 'end of life' resides in – the last few breaths. As one woman told me, her husband "was only dying in the last 24 hours" although doctors had labelled him 'end of life' earlier in the year. Although her husband had gone through the EOLC pathway, she only considered him as near the end of his life at this time, when withdrawn on his actual "deathbed" in his bedroom and moved beyond the settings of care he had been part of before. Whilst the term 'active dying' has implications for the type of medical treatment and care a patient received this is often the period referred to, particularly retrospectively by informants, as end of life due to the noticeable physical changes and professional response. Although there appears to be agreement between lay and professional categorisation of death and dying at this point, they arrive at it through different observations and interactions with the person and their body.

An example of a mismatch in classification is of differing lay and professional understandings of 'terminal'. Oscar had a rare form of a degenerative neurological condition that caused muscle deterioration over years. From witnessing how others died from similar conditions, his understanding of his disease was that it would "kill him", most likely by making it difficult for him to breathe. When he developed a bump on his ring finger that was diagnosed as cancer and lead to an amputation, he became concerned about his new disease condition. Doctors could not say if the cancer cells had spread before the amputation and Oscar and his wife were concerned how skin from the finger was used to cover the wound. This ambiguous nature of potentially having cancer but not knowing, as well as having another life-limiting condition, lead Oscar to ask his oncologist "am I terminal?". Recounting this in their living room, Oscar and his wife told me how the doctor

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diary of a woman's "awful death" on the LCP (Rawstorne 2012) and doctors admitting flaws with the use of the pathway (Triggle 2013).

laughed and said "of course not!" failing to realise that the question behind what he asked was whether or not the cancer would kill him before his other condition. Oscar considered himself already terminal because of the degenerative nature of the neurological condition; the doctor did not consider Oscar terminal as he was not actively dying from his cancer and had received curative, not palliative, treatment for it. For Oscar, it is the condition, not him as a person, which he was referring to, whereas the professional use of terminal refers to both. The doctor's inability to make this distinction lead to Oscar distrusting him, which was unintended by the doctor as he attempted to reassure Oscar about his cancer. What this scenario demonstrates is how the common use of the word 'terminal' – meaning something one will die from – is different from the clinical use, which alludes to a more imminent death, the condition, and the person. Due to the different uses of the same concept, professionals and patients are forced to interpret what the other is saying, often failing to do this perfectly as their own terms of reference – and boundaries for the category – are different. This is an example of the unintended consequence of the mobilisation of clinical terms into popular discourse and vice versa.

Although the terms palliative, terminal and active dying may be used to refer to a clinical stage or process a person is in, they are also used as a way to describe the patient. The patient therefore becomes this state of being, labelling them as "palliative" or "terminal". Whilst this may sound dehumanising, the effect of such labels frequently meant that patients received extra and special attention from those involved in their treatment and care. In some cases, as with GSF, patients themselves may seek to positively use the term to influence the care they receive. Yet there were more diffuse terms people used to describe

these states of being, and whilst not clinically based, they nonetheless informed the care people received, and these are covered in the next section.

3.5: 'Dying' as an inadequate concept

The terms discussed above are used primarily in clinical practice and mainly refer to technical processes of dying. Yet when talking more generally – as part of the lay discourse – euphemisms and more vague terms were used. The term dying itself may be left undefined and unused. Instead, people were referred to as "poorly" or "quite unwell" and this could range from being ill enough to require hospitalisation or specialist treatment, to being "close to passing".

In some instances, it may have also been the way a person referred to themselves as relative to their "normal self"; for example, one informant would say she was "unwell" if she could not leave the house even if she was not ill enough to warrant a clinical visit. Without seeing a person or being able to enquire further, such references to states of being could be confusing and to some extent misleading. The key to decoding such discourse lays in knowing the person being referred to and who is doing the referring. Her "unwell" when talking about herself meant something different to the care home manager talking about another man as being unwell; in the first instance it refers to her feeling too tired to leave the house whereas in the latter it referred to him being hospitalised with pneumonia. It is a way of indicating ill health without giving too much detail thereby maintaining private/public boundaries but allowing sharing of some information. Nonetheless notions of poorer states of wellness opened up the possibility of the listener to enquire what was wrong, if they could do anything, and wishing the bearer of poor health luck and recovery.

In this way, asserting that someone is feeling poorly and unwell enabled people to be a recipient of care and concern.

In some cases, being told a person was unwell would be followed by "they've taken a turn for the worse" particularly if someone enquired what was wrong and if they knew the person's general poor state of health prior to 'this turn'. This represented a change in the person's state of being, and when used by medical professionals (as these terms are not absent in clinical settings, especially when professionals talk to carers), it indicated a belief that the person was closer to death than he/she was before. When used between medical professionals, this term was an indication that a clinical visit was needed, where symptoms and needs could be reassessed. Occasionally staff would use this as a way to convey changes in practice to other professionals or to the patient's family. Family used it as an explanation for clinical presence or change in a person's location, appearance, or mood. Therefore, 'turn for the worse' says much and allows changes in action, without providing unnecessary details. If margins are dangerous (Douglas 1966), such as the transition from life to death, and boundaries are to be protected, such as privacy, changes in states of being that are not located in medical or bodily terms are a way of navigating the transition.

"Dying", however, was not used as frequently as one may expect. Whilst policy makers would use this observation to assert that death is a taboo, I wish to point out how and why this term is difficult to use and that it does not always mobilise the care and reactions other terms may allow for. Firstly, within healthcare, dying is sometimes seen as the job of 'others', meaning a different speciality, typically palliative care or community nursing. When talking to GPs, some would comment on how dealing with dying patients was something their district nurses did or they could refer the patient to the hospice. Within hospitals,

palliative care teams visited multiple wards and were the key staff members educating

colleagues about EOLC and filling out paperwork such as the LCP. In this way, these

specialists were the gatekeepers for knowledge and action around EOL, when dying is seen

as a process. Although they felt privileged to be in this position, many of the specialist I

spoke to wished they were involved sooner in a person's case in order to know them better

for more "appropriate care planning and provision", referring to the relational knowledge

that often underpins EOLC. It is not surprising then that they prompt colleagues to send

referrals once a patient is "palliative" before they are "dying"; being considered dying, with

the connotations that death is imminent, is already too late for the specialist to provide the

kind of care they strive to deliver.

Similarly, people I spoke to refrained from using the term "dying" generally when talking

about either their current state of being or decline towards death. One of the reasons for

this was that they presumed dying had certain signs, such as physical changes, and that one

would be aware of these, and they themselves were not in that state yet. These presumed

signs were either unknown – they did not know what to expect – or based on what they

have experienced when watching others. These could include withdrawal, refusal of food, or

in the case of certain conditions, troubles with breathing and eating. Again, dying was

thought of as something happening days before death rather than months or years;

however this did not stop people remarking that "we are all dying aren't we?". When used

in this way, there is nothing particular that can be done in response to being in this state.

The uncertainty and vagueness of "dying" makes it inadequate to describe what is

happening and for generating action as a consequence of long-term illness; it is ineffective

at categorising experience and mobilising care.

The various terms used to describe end of life, and their overwhelming basis on clinical, or biological, understandings of the body firmly places death and dying as something to be treated by the medical profession. Attempts to identify and classify dying are illustrative of attempts to manage "the dying process" with its uncertainties, changes in physical and other needs, and overall representation. Alluding to changes in states and being, rather than directly indexing dying, can mobilise care in other ways and therefore actively defining dying is not the only way of addressing (physical) changes at the end of life.

3.6: Conclusion

In this chapter, I have demonstrated how the category of 'end of life', and the 'care' that is associated with it, are created within a particular political and social context that privileges certain ideas and experiences of death. This is an example of how healthcare policy attempts to realise abstracted theories and categories. In effect, such categories have practical implications for how people are seen as 'dying patients' through bodily decline, and that death, once it is deemed foreseeable, can be managed within a medical rubric. The concept of 'end of life', however, cannot be applied to all deaths, even if everyone at some point will die. Instead, it is a strategic term for grouping together patients who are likely to die from medical conditions that can be tracked over time, as demonstrated through the use of dying trajectories. Moreover, end-of-life care is focused on providing good deaths in these cases by placing patients on 'the EOLC pathway' which encourages health professionals to co-ordinate care services around the model of advance care planning, which is the anticipation of future care needs. In the next chapter I explore the notion and practice of advance care planning further.

Although EOLC policy seeks to provide 'good deaths' to patients, the understanding of

'good death' is bound up in a context in which not only medical practice and understanding

of death are displayed, but also where social theory and debates are born down on to the

concept. Incorporating such ideas into policy is an indication of sociolization, and reflects

the embedded nature of current healthcare systems and the importance of understanding

the wider social context and history when analysing health policy. This incorporation,

however, does not mean that policy is without its own direction and agenda. In the case of

English EOLC policy, the aim to tackle the 'death taboo' is perhaps not supported by popular

demand or academic research; indeed, referring to 'dying' may not have the same impact in

terms of generating socially appropriate reactions as policy makers would posit. Not

referring to death explicitly does not mean, however, that people are unaware of 'death' or

the likelihood of 'end of life'; rather it represents the nuanced ways in which death and

dying can be communicated and related to, of which the official policy version is one of

them.

Chapter 4: Creating Choice

4.1: Advance Care Planning, Choice and the Patient-Subject

The previous chapter demonstrated how defining end of life enables particular ways of viewing and relating to death and the dying person. By figuring out and constructing which dying trajectory a patient is on, healthcare professionals can tailor the care provided, seeking to ultimately manage the dying process and achieve a good death. Advance care planning (ACP) is a key element of this management, centring on the concept of patient choice, often referred to as preference. This chapter explores in more detail what ACP is, how 'choice' is a goal in EOLC policy, and how choice and the patient-subject are created through practices of 'doing choice' in EOLC. This analysis is based on a review of policy documents, developments and events as well as interviews with patients and healthcare professionals. Through the practice of ACP, using forms such as the Preferred Priorities of Care document (PPC), a particular version of the patient and their preferences becomes knowable and the subject of care work, a theme that will be further explored in the next chapter, although these are influenced by the very forms and services in which patient choice is part of.

Advance care planning (ACP) is blanket term used to describe a number of processes and interactions that seek to imagine, prepare for, and monitor future care needs.[47] ACP facilitates the process of anticipating and responding to changing care needs as well as representing a physical plan (document) that illustrates the proposed course of action. A

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[47] Throughout this dissertation I used the term 'needs' as it is used emically. This primarily refers to symptom management, such as pain relief, and adapting to decline in physical mobility. This comes under the term 'care' as the patient typically requires the assistance of another person to ameliorate these changes.

key feature of ACP is that a patient is able to express their wishes for future care, such as where they would like to be cared for, and this is to be recorded in the plan. At an international conference on ACP it was joked that it could be "both advance and advanced care planning", illustrating that not only should planning happen in advance of changes in care needs, but also that thinking ahead allows plans to be more thought-through and tailored to the patient or care situation. This is considered to be "advanced" as it represents patient-centred care, which is currently considered best practice within the National Health Service (NHS) and other Western healthcare systems. Whilst ACP can in theory be used for any care situation, it has found a particular niche in EOLC in that it builds on previous models of planning ahead for death, such as living wills, declarations of refusal of treatments, and clinical practices of administrating do-not-resuscitate forms. In this way, ACP is an extension of current social and clinical practice.

   ACP is part of a longer history of patient-choice within the state-provided NHS. 'Choice' was part of the foundation of the service as patients were encouraged to choose a doctor when the NHS started in 1948[48] and since the 1990s this has expanded to a more consumerist model of choice where patients are active decision-makers about their treatment and place of care, and quasi-market forces altering the delivery of health services (see DH 2003). Whilst not as extensive as the American model where patients often demand treatment,[49] the NHS has increasingly moved from a system of default processes to involving patients in their care plans. With this shift in healthcare models, patients are framed as 'users' rather than passive recipients of care, subjects that wish to have a say

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[48] This is evident in a promotional video released at the time encouraging people to choose their doctor. Video available via BBC Wales (2006).
[49] See Timmermans (1999) in the case of CPR in America; in the UK patients cannot demand this treatment (BMA *et al.* 2007)

about their health and care and the health service shifted from providing treatment and care to offering options in these areas as well. Within EOLC, ACP is an opportunity for patients to express their preferences – to state a choice – about the manner of their death. This positions patients as autonomous beings, able to express themselves and anticipate their future needs and wants.

  The NHS 'choice consultation' of the 2000s positioned choice as a way of improving patient experience rather than an end in itself (DH 2003a). This resonates with development discourse focused on empowerment and participation (see Cooke and Kothari 2001).The value of choice is in the act of offering alternatives and following patient preference. Similarly, in EOLC policy 'choice' is seen as a goal and solution to previous dying experiences, allowing a 'good death'. As way of illustration, key non-professional advocates of the EOLC policy publically speak of how the simple question of "where do you want to be" and following the answer positively changed the dying experience of their loved ones. Articulating where one wants to die and having that wish followed is proclaimed to be the "best we can do" in this "last chance" before death. Being able to articulate one's preferences is viewed as expressing autonomy and agency, which are both valued in the cultural context, and therefore fulfilling one's last wish is considered an ultimate form of respect and way of honouring the individual before they die and can no longer express themselves. With 'choice' in other aspects of daily life and healthcare, offering choice near the end of life is a way to 'normalise' patients, treating them as individual subjects. Choice is therefore not only a goal – something to be offered – but a solution to the problem of death and dissolution of the person as it signifies their ability to be an active subject even as they die.

The process of ACP and expression of choice at the end of life is to theoretically help

patients and professionals prepare for the forthcoming death. Patients are to be reflexive,

expressive and autonomous subjects, able to be aware and accepting of their deaths whilst

health professionals are positioned as empathetic, and able to predict and communicate

likely clinical outcomes. Within EOLC policy autonomy is understood as being self-governing

and acting of free-will, in the neoliberal tradition (see Rose 1999), and is similar to the

prevailing ideology within Western societies that individuals are the masters of their own

lives and should determine every detail (e.g. Salecl 2010). Drawing on philosophical models

that link autonomy with personhood,[50] ACP is seen as a function of expressing personhood

through choice. By positioning choice as central to a good death through ACP, particular

notions of what it means to be a person – to be able to choose and to make informed

choices – are valued and supported. Moreover, how the outside world and one's body

should be related to are also expressed; by enabling choice the body and future body must

first be knowable and then positioned as manageable, as illustrated in the previous chapter.

ACP is therefore an expression of post-Enlightenment values about what it means to be a

person in the world.[51]

Although choice may be said to convey "our nature as human beings" (Randall and

Downie 2010:5) and foster wellbeing (Schwartz 2004:3), it is an oft critiqued concept.

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[50] See Schneewind 1992 regarding Kant.
[51] Yet ACP also creates other subjects beyond the 'autonomous patient'. Professionals, and the care system at large, become not only reactive to patient needs, but anticipating and adaptable to them. This can be contrasted to how institutions, like the NHS, are often viewed as inflexible professional-led organisations. A focus on patient choice therefore changes what it means to be both a patient and professional within the healthcare system. There is a third, invisible subject within ACP and that includes the wider audience of the forms, such as the family, with whom the forms should be shared. Their presence, and support, is presumed within the model of EOLC, positing them as subjects that are willing to sacrifice their own autonomy to support that of their dying relatives. These non-patient subjects are discussed in more detail in Chapters 5 & 6. How institutional and conflicting choices are weighed up within ACP and care practices is not clear within EOLC policy; the centrality and indivisibility of patient choice itself outweighs these concerns.

Giddens belittled the 'freeness' of choice in his remark that in contemporary society "we have no choice but to choose" (1991:81) whilst others have illustrated that more choice and choosing does not necessarily make people happier (Salecl 2010; Schwartz 2004). Moreover, rational choice theory, which is built on Kantian interpretations of autonomy, has been contested as people can choose subconsciously (Salecl 2010) and make seemingly 'irrational' choices (Ariely 2008). Although people may be 'free' to choose, their choice may be affected by many things creating a framing effect. These can include social influences, such as the doctor-patient relationship, and the alternatives presented (Ashcroft *et al.* 2001). Therefore choice, although often expressed as a positive expression of autonomy, can actually be restrictive and restricted. Moreover, in the context of death and dying, there has been considerable debate about how much choice – and consequently control – people should and can have over death (Kaufman 2005, Green 2008). Whilst in other aspects of healthcare, choice is viewed as enabling and improving health (and thereby avoiding death), within EOLC choice is more contentious as it represents the possibility to acquiescent to death and/or challenge the course of 'nature'. This alludes to larger debates about the role and ability of human beings to control their environment and 'destinies' (Lock 2002). What choice is and how it is exercised is therefore not as unproblematic as the use of the concept within health policy implies.

A consequence of choice is responsibility. Within English healthcare policy more generally, 'choice' is viewed as a mechanism to empower patients about their own health (Coulter 2002). By offering patients choice and informing them on how to improve their health behaviours, patients can (to some extent) be held responsible for their health status (see Galvin 2002). Within EOLC, patients are to be 'empowered' by actively thinking about and

planning for their deaths. Yet, does this mean patients are left responsible for the quality of

their dying? Particularly, as the following chapters will illustrate, choice and EOLC are not

singular events and as noted in previous chapters, death and dying are viewed as

influenceable but not necessarily controllable. Lawton (2000) illustrated how dying bodies

can be messy and deviate from what people expected to experience towards the end of life.

As one dies, their body may become subject to the treatment of others – health

professionals administer medications and family members may assist in cleaning and

toileting. A person's agency over their own body is challenged as it dies in these

circumstances. Expressing a choice over place of care, for example, does not equate to

having the ability to actively influence the type of interactions one is part of. Consequently,

the relationship between choice, control, responsibly and dying is complicated and requires

a more nuanced understanding of how 'choice' operates within EOLC.

   Such critiques of choice illuminate the prominence of the choice ideology in English

society, let alone current healthcare policy. In societies where individual choice is privileged

over other values, the singular person is disconnected from others in a logic that seeks to

maximise self-gain. However, whilst the act of 'choosing' may be seen as part of human

nature, the notion of 'choice', particularly rational choice, as an ideal is more abstract and

like the individual, disconnected from those around it. Repeatedly people's choices have

been shown to be other than rational and constructed through interactions and by the

world around the person 'choosing'. Just as people are connected to others through their

relations, in practice, choice is embedded in a wider web of practices that are not as insular

as individual autonomy and rationality suggest. Understanding that 'choice', and therefore

the choices people make, is more complex and influenced by other factors outside of the

'rational mind' helps to illuminate how choice is created within the end-of-life care context. It is this influence that is discussed in this chapter.

Advance care planning relies on patients and health professionals being aware and discussing the patient's forthcoming death and anticipating what the patient may need and want as their health declines and when they die. This positions the patient as a reflective, forward-thinking individual that can, and wants to, make decisions about unknown future situations. The emphasis on choice is situated within a cultural context that endorses personal autonomy and rational thinking, yet 'choice' and the patient are both embedded within webs of interactions and influences making them neither fully disconnected nor abstract. This chapter demonstrates how choice within end-of-life care is part of a larger move towards patient-centred care and provided as a goal, and mechanism, for achieving a good death. Through discussions of imagining the future to using tools that 'enable choice', such as the Preferred Priorities of Care document, I demonstrate how not only the dying person is created as a subject, but how choice is constructed as an ideal that presents patient preferences as independent despite the socio-political and material aspects that influence stated wishes.

4.2: Imagining Futures: Choice in End-of-Life Care

A key element of advance care planning is the ability to imagine the future and play out various possible scenarios. Whilst this includes being able to foresee decline (see previous chapter), it also includes more generally imagining what death and dying can be like. ACP is a particular range of imagining the future, focusing on care needs and preferences but imagining 'choice' in the context of EOLC is larger than this. This section focuses on how the future is imagined through a lens of choice, or being able to express a desired kind of death,

by reflecting on previous experiences. In this way, choice for the future is knowable both through the present in thinking about 'choice' and the past through previous experiences.

As noted above, choice in EOLC is positioned as a solution to the previous trend of patients experiencing deaths that were not entirely 'good', being either in the hospital, without the chance to accept death, or lacking dignity. One way of making sense of choice as a solution to the "horrors of death" comes from EOLC policy advocates who draw on their own experience of death and dying. For example, in one case, a couple described the rapid decline of their son's health as he unexpectedly died from cancer in his 30s. After recounting several instances of miscommunication with doctors, "last trips" to see the world, and the hope they had, the moral of the story came when they shared how a single specialist nurse asked their son "where do you want to be" and got him there "so he could die". At this point their son no longer wanted to be in the hospital fighting, but at home in his own adult space, something the couple had not even contemplated or realised until then, and yet, on retrospection, "made all the difference to his death". As his parents viewed it, and as they wish their audiences to interpret the actions, respecting and fulfilling his choice about where he was to be is therefore linked with enabling him to have a good death. Similarly, in interviews and casual conversation others have told me that 'choice' – understood broadly – at the end of life provides a moment to have control when one really has no choice about dying. The offer and realisation of choice transformed death by making it less about the disease and more about the person, especially "in those last moments". The aim of policy is therefore to expand this trend to all of those dying, not only transforming individual experiences of dying but the larger social landscape of death. A key message from policy events about EOLC is that "brighter future" for "all of us as we die and

care for the dying" is imagined through the provision of choice at the end of life. There is an underlying assumption within this narrative that articulating a preference for where one wants to die makes that a possibility that can be turned into a reality.

This future is possible to imagine because the couple experienced a glimpse of it with their son – they saw an alternative way of dying than the one they were experiencing up until that point. They were positive about the "sea change" they viewed within England as more people were offered the choice their son was. Yet this ideal of choice is in some respects a subjective ideal based on their personal experiences that was being played out and expanded on a population level. It was presumed that because 'choice' enabled their son to have a 'good death', it will do the same for others and therefore all should be offered 'choice'. This doctrine of choice, however, undermines personal expression to not choose, and more importantly, to not be aware of one's death (e.g. Barclay *et al*. 2011). Moreover, by focusing on one kind of possible future – better deaths through choice about place of death – other possibilities of reforming death and dying are left unexplored. This is perhaps because they are as yet, unimagined since their possible formations have yet to be experienced. Choice as a policy goal for the future is taken from selected past experiences of a few to represent the "best way" and new standard of dying in contemporary England.

Similarly, how people imagine their own deaths is influenced by their previous experiences of death. For Evelyn, a retired doctor recently diagnosed with a degenerative neurological condition, her version of an ideal death was informed both by family and professional experiences – these "things that have influenced" how she wanted to die. She was aware of what symptom relief could be expected and knew how to express her concerns. An important factor when contemplating how her death might be was that both her father and

her friend were able to die peacefully in her home; family and friends acted as guards, regulating who came to visit when, including the nurses. Although retired, Evelyn was acutely aware of current debates about EOLC, including the importance of place of death. She felt confident that since her "children had witnessed these good deaths" with both choices in terms of place and access, they could enable her to have a similar experience. In this way, the shared past experiences informed what Evelyn could envision for her own future death, projecting the past into the future. It is through the experiences of the deaths of others that Evelyn is able to think about what her death could be like and what she would like. One's end-of-life care choices, which are thoughts about the future, are therefore influenced by what one can imagine about one's own death based on what one has experienced before, although these experiences are not necessarily about one's own dying process but what one has witnessed as others have died.

These two examples show how previous experiences help make choices about death seem clear, both for the individual and on a larger societal level. Yet in conversations with Christina, who had multiple forms of cancer and openly talked about death, the different experiences of her family and friends as they died made it difficult to articulate what she would like best. From her perspective, her mother died too suddenly and her father's death was "drawn out" – she wanted neither of these but did not know if there was something in-between. Having witnessed her brother's "horrible death" at home and known her neighbours to die peacefully in their sleep in their own beds, she recognised that a home death could be possible "no matter how bad you are". Reflecting on how her children reacted the last time she was seriously ill, Christina was unsure they could cope with her at home and soon within our conversation the hospice became a viable alternative, as she

claimed that "if you're going to go with cancer, they are the best places to go" as other friends had experienced. Cumulatively these events, and her changing interpretations of them over time and within the same conversation, played into Christina's ideas of her future death, each one being emphasised at different times and subsequently her deliberations about the future. This account demonstrates that whilst for some, and particularly in policy, there is a simplistic connection between place and the kind of death one will have, for others, past encounters with ill-health and death project a more complex image into the future. This complicates the role of choice in being able to articulate and fulfil an ideal dying experience.

Imagining the future through a spectrum of choice allows for various scenarios to be played out in conversations and within policy-making. Yet, these projected futures are made up of images from past experiences, which shape and have been shaped by the person articulating them. What is imagined may not necessarily be about care needs, but the interaction between people and spaces, which hold meaning for how a person is viewed. Salecl (2010) notes how life choices not only create alternative futures, by thinking about the possibilities, but reinterprets the past. This can be seen in all three examples above as the each past experience of death is re-evaluated by the present values of what the person now considers to be 'good'. In Christina's account, various aspects of deaths, which may otherwise been seen as contradictory, such as wanting to be both at home and in the hospice, are both thought of as good as she imagines how it could be. Advance care planning is about making decisions in the present about the future, but how both the present and the future are understood is through how people project the past and engrave the values of choice and good death onto these lived and imagined experiences. End-of-life

care choices are therefore about imagining what may come, both on an individual and societal scale, by reflecting on the past. Choice – what people may declare as their preferences and what is presented as choice in EOLC – is as much a statement about the present and anticipated future as it is about one's by the past experiences. More generally, popularised experiences of past deaths, either as good or bad, influence the way policy makers shape the way dying is to occur and be understood, in particular by emphasising the role patient choice can have in creating a 'good death'.

4.3: Ways of doing Choice: Forms and Documents

Since choice is a goal within EOLC policy, practitioners need a way to operationalize the preferences patients express. The previous section describes how 'choice' is a matter of imagining the future on different scales through past experiences. If the previous section is about choice as an imagined, and changing ideal, in this section choice – and the preference-expressing patient – become a more fixed and known entity. I will use the example of the Preferred Priorities of Care (PPC) document to explore how a 'choice document' allows for the patient as person and the patient's preference to become knowable through the act of documenting. Riles (2006a, 2006b) notes that documents are a ubiquitous feature of modern life, referencing a societal desire for transparency, the exchange of information, and a public record. She also illustrates how documents are active agents in modern life, how they shape things and practices; documents are more than mere forms but play a role in what they make possible. The use of documents in EOLC, like the PPC, are part of these cultural practices and values, creating choice and the dying patient as something that can be publically known and shared. This section therefore focuses on how 'choice' becomes knowable and actionable in practice through the use of forms and documents.

In order to enable choice within the NHS, a number of 'tools' have been devised to enable health professionals and patients to navigate the options within the system and express preferences. Within UK healthcare, tools – which can be anything from forms to prompts on the computer – are seen as aids to "good clinical practice" as they enable and encourage practitioners to ask certain questions (either to themselves or of patients), follow certain clinical pathways, and arrive at more accurate/appropriate treatment or care. The emic use of the term tool is indicative of its purpose – an object to be used to help complete the task at hand and achieve the goal – and they are often created alongside clinical practice to solve a local problem about clinical care provision. Outside of the context of EOLC, an example of such a tool is the 'choose and book' system that opens on the computer screens of GPs when they are referring patients to hospital services listing all available physicians and hospitals for the procedure. Frequently patients continue to visit the nearest hospital (Kelly and Tetlow 2012), but the principle behind the system is that patients are offered a choice and make decisions to suit them rather than be subject to the default of their doctor's choosing. The automatic launch of the software platform reminds and enables doctors to provide patients with this information. Tools designed around choice are therefore part of NHS clinical practice and interactions and can be viewed as aids and enablers of patient choice and patient-centred care as they force professionals to consult the patient on their preferences.

In the context of EOLC, tools that enable ACP, such as the Preferred Priorities of Care (PPC) document, serve as a mediator like the 'choose and book' system between health professionals, patients, and service options. These are provided or used by health professionals with patients identified as being in the last year of life and therefore at the

end of life. They are designed to enable "difficult conversations" about death and dying and to encourage patients to think about their future and where they would like to die. The material properties of the PPC will be discussed in the next section and how the PPC is used in practice is the focus of the next chapter; here I highlight how forms like the PPC document construct the patient and their preferences as knowable and sharable information.
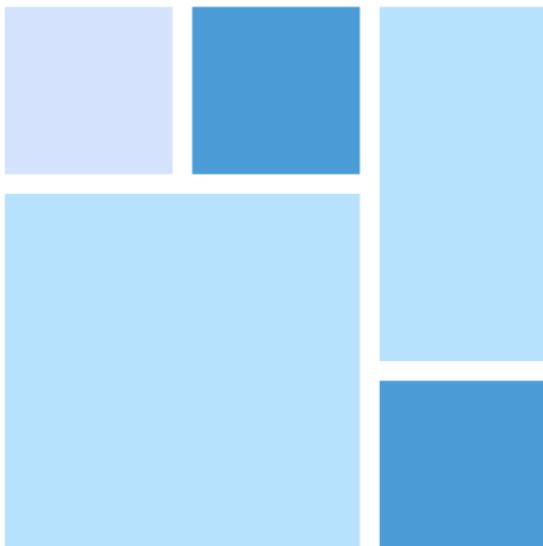
Image 8: Front cover image of the Preferred Priorities of Care document. There is space on the top of the page for individual NHS trusts to put their own logo on it to tailor it to their services and make it recognisable within their organisations

The PPC document is intended to encourage reflection and discussion about end of life care, particularly what the dying person would prefer to be part of their care. In this way, it asks people to envision multiple possible futures based on, among other things, the information they currently have about their condition, how they feel, what they have previously experienced, and what they think they would like to experience. It is meant to be for and about the patient and directs itself at 'you', the person completing the form about whom these preferences relate. In this way it invites self-inspection although these are within the confines of the form as well as clinical and care practices. By documenting their preferences, which as 'choice' are understood as

indicators of individual autonomy, the form is used as a way to access the person (and personal) behind the patient. This information is to help professionals 'know' the person/patient and consequently organise care to be person-centred. As one nurse told me, being able to know what the patient may like helps "know them better…and think about what they may want". By asking about choice, the PPC document is used as a way to gain insight into the person and to think laterally about them and their care.

These tools may be in the form of computer software, or as frequently in EOLC, in physical paperwork. As material documents or in patient notes, they are not only tools that enable the selection of options but enable 'choice' in other ways as well beyond the act of choosing. They can mediate a patient's trajectory (e.g. Berg 1996) – by selecting one option instead of another the services and kinds of treatment available to a patient differ. For example, patients refusing cardio-pulmonary resuscitation (CPR) in advance in the form of an advance directive (another form of ACP)[52] are less likely to receive the treatment than those who do not have such documents in place (Beach and Morrison 2002). Patient preferences for place of death are often taken from PPC documents and replicated in other forms, or the entire document is copied and sent to other services (see Chapter 5). Within EOLC where co-ordinated care is seen as paramount as patients move between services, these tools and documents similarly follow – or even precede the patient in transfers – to allow more professionals to be aware of the patient's preference. According to the nurses I spoke to, if patients arrived at hospital with a PPC stating they wish to die at home, staff are encouraged to actively work at discharging them as soon as possible. The plans therefore

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[52] Advance directives can also be known as advance decisions to refuse treatments (ADRT), particularly in England as patients are able to refuse, but not demand, treatments. For these documents to be considered legally valid, they must bear the signature of a doctor. The PPC does not require any medical professional to undersign the statements.

provide a material for basing action on (see Suchman 1987). Advance care planning is not only the action of choosing, but the materiality of choice and how this impacts patient courses within (and out of) the healthcare system, care and service delivery. The goal of choice is not only in providing options but providing means in which those choices can travel and be known within the wider healthcare system.

In this way, documents are strategic in nature – they are used to elicit particular information at a particular time and to inform action. They are also strategic in how they transform the subject (e.g. Reed 2006); in this case, the patient is transformed from a potential receiver of care to a reflective subject that can anticipate and articulate future wishes. In turn, one may begin to relate to themselves differently, including viewing themselves as dying and actively preparing for that death. From a Foucauldian perspective, this transformation of the patient-subject also has implications for the clinician-patient relationship, changing the interactions they may have based on the accounts of preferences, such as discussing death more regularly. Through the documentation of patient preferences, the patient and their 'choice' can be monitored. Policy encourages this surveillance of individual and population-level patient choice through the comparison of documented choices with 'outcomes' such as place of death, which is routinely collected on death certificates, another form of documentation and record keeping.[53] In this way, documents such as the PPC alter their subjects and objects as they and the content created within them are interacted with and used to inform action outside of the form.

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[53] See Cohen *et al.* 2007 as an example of how such information is used in research to inform policy.

4.4: Influencing Choice: Constructing and Structuring Choice

The previous sections have explored how through advance care planning, various subjects – such as the patient as person – and objects like the documents to enable and capture choice are constructed and constructing new ways of thinking about and interacting with people near the end of life. From an actor-network theory perspective, it is reasonable to assert that non-human objects have their own agency (Latour 2005). This means that they exert some influence over other agents within the network and play a role in the social action and processes of which they are part of. In the context of advance care planning, the PPC document is not only a tool used by professionals and patients, but an object that they interact with. Moreover, the contents of this object, and its material properties, help shape the ways in which the document is interacted with and the conversations that spin around it. This section describes how the materialities and text of the PPC document inform the preferences and choices that are then later recorded within it, including determining what is counted as having legitimate space within the form. In this way, the PPC document is not a neutral form or holder of 'choice' – as was assumed by health professionals in practice – but an active co-constructor of 'the choice'.

Although I use the word agency here, this is not the same as saying the form is solely responsible for what is later inscribed within it. The completion of the document is ideally to be done after considerable deliberation on the part of the patient, and in conversation with those who care for them including family, friends, and professionals. All of these actors, with their various and often complicated intentions and opinions, are part of the process of defining and declaring choice. Likewise, the form has a role in this process in terms of framing, guiding, and enabling this process. I will therefore talk about the form's 'influence'

rather than agency to highlight the perhaps subtle way in which this is done whilst also foregrounding the actions and intentions of people as they interact with the form and decision-making.

The literal and metaphorical backbone of the form is the three questions that relate to 'you'. These are located on the middle pages of the document, headed under "Your preferences and priorities" and this is where the document naturally opens to due to the staples down the middle. It is relatively sparse and the two sides are divided into four sections, two on each page (see Image 9). Three of these spaces are dedicated to direct questions and the last space is for changes to the previous three answers, which like the original entry should be dated and signed (although it does not say by whom but implies this is to be done by 'you' as an indication of validity). The pages therefore follow a linear order of: 1) "In relation to your health, what has been happening to you?; 2) "What are your preferences and priorities for your future care?", 3) "Where would you like to be cared for in the future?" followed by a space for a single signature and date; and 4) "Please record any changes to your preferences and priorities here. (Please sign and date any changes)".

Since this is where the document opens up to, based on my observations and conversations, these are the first impressions many people have about the form and what they are to do with it. They are supposed to directly answer these questions and the content of questions informs the reader as to what the content of their answers should be (see Brenneis 2006:65). Some research indicates that many people in Western countries read in a Z pattern (e.g. Holmqvist *et al.* 2003) rather than a linear or chronological pattern. Looking at the PPC document, this means that many people would read questions one and three first. Similarly, in advertising the most important and expensive space is the top right

hand corner as this is the location eyes settle on first (Nikola 2013) – for the PPC document this is where the question about place is located.[54] How questions are framed, both in terms of content and in the physical space, has implications for how they are answered (Schwarz 2004). With these theories in mind about how people 'read' a document, it is not surprising to find that people begin to answer the question about preferred place of care in other aspects of the form or in their discussions of other questions. In this way, the practical layout of the PPC document informs how people begin to engage with the wider project of thinking about future priorities and preferences, quickly narrowing it down to a matter of place. Interestingly, this consequential emphasis on place mirrors the relatively high position place of death has in EOLC policy.

Your preferences and priorities
In relation to your health, what has been happening to you?

Where would you like to be cared for in the future?

Signature   Date

What are your preferences and priorities for your future care?

Please record any changes to your preferences and priorities here
(Please sign and date any changes)

Image 9: Inside of the Preferred Priorities of Care (PPC) document illustrating the four questions and their relative spacing. A full copy of the document can be found in Appendix 6.

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[54] In discussions about the design of the form, it is intended to go from general to specific, and therefore the positioning of the place question in this prime position is coincidental.

The following examples illustrate how place of death becomes the primary object of choice as people interact with the PPC document, even if other aspects of their death may come to the fore in our conversations. For example, Norm told me he did not previously think of his care in the way the PPC document, provided by the hospice, suggested. Nonetheless, now that he had the form he was resolute to "complete it" and to "stay at home if I can" unless he needed more medical treatment in which case he would go to the hospice. He wrote "home, unless necessary then hospice" in response to the question about preferences and priorities for future care. The only other information he included on this two page spread was that he had progressive liver cancer whilst his signature and date completed the form. No other preferences or priorities were listed and the third question, directly asking about place, was left blank as he figured his previous answer sufficed. He had filled the form out in a chronological manner but had considered the issues as one and the same.

Similarly, when speaking to Christina about her form, she directly addressed the issues raised by the third question even as we progressed through the form in a chronological fashion after she had briefly read it. Interestingly, when talking to people about the future who did not have a PPC document or had not (yet) come into contact with one, the element of place was not usually the first to be mentioned unless they had a significant negative experience of a particular care setting or where in hospital and wanted to be elsewhere. Instead people often talked about what it might be like for their family and those around them. Similarly, recent polls indicate that place is not a top priority for dying people (Waghorn *et al.* 2011). These descriptions and comparisons indicate that the design of the PPC document has a role to play in foregrounding place of care, and ultimately place of

death, as something that needs to be considered and stated in order to achieve the best care (and a good death).

Although it might become used only as a capture of preferred place, proponents of the PPC document will argue that it is also to be used to think about other preferences or priorities people may have and such discussions and declarations can be useful in advance care planning.[55] What these other aspects might be are not explicitly asked about like place is. Instead, other facets of care are left open and broad in terms of "preference", "beliefs and values", both in the main question and in the accompanying pre-text where only place is explicitly mentioned. These other issues are quite open-ended and yet the space provided to document one's views on them is the same as for place, therefore simultaneously encouraging and discouraging readers to engage with these issues. During my observations, people may discuss these issues but often made no attempt to document them in the PPC form even if they later chose to state a preference for place. In addition, people would discuss options like refusing treatments in advance only to be told that these require another form, which is legally binding, such as an advance directive. So although the PPC form may entice people to think of such options and potential futures, it does not formally allow decisions about them to be considered as legitimate or legally relevant within the space provided. It therefore becomes a document that cannot capture all the issues thinking about future ways to death can lead to.

Overall, the way the form is laid out in terms of the order of the questions and the supplementary text informs the types of futures and preferences that are considered and

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[55] Although in its initial design place was a key factor in the creation of the form. Place of care and death are viewed within English EOLC policy as factors of the dying process that can be influenced and measured. The PPC form has been incorporated into national policy as it enables conversations about dying and 'choice', and can be audited as a tool to monitor changes in care provision.

later included. Place is foregrounded and is often the only preference listed, although other issues may be discussed and be more important for the individual tasked with completing the form. For people who find it difficult to think about the possible futures, let alone make a choice for which one(s) they would prefer, the form does not allow for them to capture this ambiguity other than through leaving it blank, which could also be interpreted as not having a preference. The layout and content of the form therefore contribute to how choice is constructed and what counts as choice in the context of end of life care.

  PPC forms are thought to be "making a statement" about yourself for others to read, as several participants noted, because of how they were to be used in clinical practice. Whilst people are reminded that their preferences can change, and are indeed encouraged to modify what is documented if they do change their mind, many commented on how enduring, and therefore static, the document "felt". Several people stated that they did not do any formal advance care planning for this reason. In terms of the PPC, the form is made of glossy paper making it impractical to use a pencil, which could easily be erased and amended. Nurses often recommend the use of ballpoint pens and I have seen a patient type out and glue in his responses because he found it difficult to write on this material. Since such mechanisms of writing are typically considered more permanent, or at least harder to alter, this led to some people delaying writing down their preferences as they wanted to be sure they "got it right the first time". Moreover, when they did write something in the spaces provided, they wanted to make sure it was legible as this was assumed to increase the likelihood that choices would be followed, often having their spouse or nurse write the dictated answers for them. These methods of completing the form, which are responses to the make-up of the form, entail added work and people. This challenges the ability of the

form to capture the individual reflective moment(s) the 'choice' within them implies. Although the PPC document is presented as flexible and evolving, the material characteristics of the form and the physical work that is involved in completing it, such as ensuring legibility and using particular writing instruments, make is less likely to be completed or altered.

The form performs a role in how choice is documented and acted upon through its material properties, including the text within it, and the practices in which it is involved in. The form, in its professional appearance and through the statement within its preface, encourages certain behaviours on the part of the patients – they are tasked with completing the form, which involves not only writing down their preferences, but thinking about what these might possibility be and discussing them with others, as well as continuously evaluating their preferences and making any changes to the document that are seen as necessary as preferences change. Whilst it may look like a one-off task, it is actually demanding a process of reflection that involves engaging with the form and what it is indexing. Overall completion of the physical form is encouraged with the claim that this will benefit the patient's care and patients often feel they should fill out the form. However, completing the form is not a straightforward task as it demands continual engagement and yet, the material properties, make such flexibility difficult.

4.5: Discussion and Conclusion

This chapter highlights the premises of individual autonomy, reflection, and choice that are inherent in advance care planning. Since ACP is posited by policy makers as the ideal solution to managing dying, and 'end of life' is itself a constructed category, it is interesting to see how the positioning of choice both politically and practically constructs particular

kinds of persons and decisions. On one hand, 'choice' at the end of life is represented as an

opportunity to express one's individual preferences. Yet, on the other, the tools of doing

choice, such as the Preferred Priorities of Care document and even the extent to which

'choice' is promoted, underline how 'choice' in this context embodies more than the

motives of the individual chooser. Indeed, choice is influenced by factors that are not all

together visible at first within the notion of ACP.

   This raises several questions about the purpose of 'choice' within ACP and EOLC. Firstly,

there is the tension between what is listed as one's choice as being a strict construction –

that is dependent on external factors – and what a person 'really wants', which implies

independent reasoning. I could brush this tension aside by sweepingly asserting that all

things are social constructions (Berger 1991; Hacking 1999); however, this does not help

disentangle the issue or help in terms of thinking about personal agency. This is why I

choose to use the term 'influence' earlier in the analysis, as a way to demonstrate how

outside factors can affect the decisions made without implying direct causation. Moreover,

when reflecting on how people used previous experiences to inform how they imagined the

future, this demonstrated that even within a rubric of influence generated by the same

material prompts there could be individual variability in terms of how this was understood.

The tension is between the discourse of individual choice and the examples of how 'choice',

as expressed, is co-constructed through the forms, policy, and past experiences that are

called upon when a person is faced with stating a preference. The examples of how choice is

done in practice in the next chapter further illustrate the co-constructed nature of choice.

   This discussion, however, does not solve the issue as to whether or not the preferences

stated are what people "really want" and this was indeed a question posed to me by several

policy makers and healthcare practitioners in my research. Such a question is beyond the scope of this study as I do not assert to know, or to even be able to know, what people 'really want'. Moreover, I am not sure people themselves are able to say definitely what they want as responses are prompted by the question. Yet, I am willing to claim that what is listed as their preferences can stand as that – given the context in which those declarations are made. Should the context change – such as the scope for preferences be widened beyond place – what is stated could well change and place, for example, may become less of a priority. Context about how 'choice' is done, how people engage with forms that illicit their preferences, and how those preferences are influenced is therefore important for understanding what 'choice' is.

Furthermore, Thomas (2005) has highlighted that in the context of EOLC, choice about place of death is highly contingent rather than categorical. In effect, people do not and cannot always die where they prefer. Whilst the discourse of choice implies that imagining and articulating a preference enables it to be "a reality", many people do not die where they choose to (Gomes *et al.* 2011). Where a person actually dies is influenced by factors besides, and in addition to, their choice. For example, if a person requires more physical care than can be provided in the home, either by family and friends or formal social and health care services, they may be transferred to hospital or care home where they later die.[56] As one dies, even with an expression of choice that represents their personhood, they are ultimately subject to being a patient within a wider healthcare system. Dying is treated a medical condition that demands a response, and whilst choice (about preferred place of

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[56] See O'Brien and Jack 2010 for further discussions of 'barriers and facilitators' to home deaths for patients with cancer.

death) represents an shift towards tailoring care, it does not necessarily replace other ways of relating to death and dying that remove it from the clinical gaze.

An underlying issue within this chapter has been the interplay between personhood and patienthood. Within choice discourse that focuses on the individual, personhood is understood to encompass an individual's preference and the ability to articulate and fulfil that preference – similar to the notion of informed consent (Strathern 2004), choice actives the whole person as a subject. As a way of tapping into the idealised value dignity and moving away from degrading images of how patients have been treated in the past, EOLC seeks to enable this kind of choice through advance care planning. The act of requiring 'choice' as part of care creates the person as a patient-subject. In this way, EOLC is an extension of medicine that seeks to make the patient a subjective object (see Arney and Bergen 1984). Rather than viewing choice in this context as one of individual personhood, it is a reflection of patienthood. That is, it embodies and represents what it means to be a patient within English EOLC. People are related to as patients, and come to relate to their future deaths, in terms of patient care as they envision where they could die. This is an example of Foucault's (1973) argument that people become subjects of a medical gaze – through advance care planning, people become patients who can be treated and related to as such, not just through their bodies (as illustrated in the previous chapter) but through their choices and how they imagine their future death. If EOLC is considered to be a response to understandings of the modern self (see Walter 1994), incorporating choice into care is a way of managing the self that reflects neoliberalism (Gershon 2011).

Another issue raised within this chapter is the factor of imagining futures and how ACP and the promotion of choice are essentially about thinking about the future. As I noted

earlier, the past is often used as a way of imagining the future, projecting past experiences onto future possibilities. The issue I wish to raise here, though, is whose future are we supposed to be imagining when ACP is taking place? At first, it appears obvious that it is to be the patient's for whom the planning is being done in name of. However, the emphasis on a system-wide approach and the 'need' to offer "choice to all" show that it is not just the individual patient whose future is up for grabs but a wider population and healthcare system that can be re-imagined. This re-imagining of the wider picture in turn affects what kinds of individual futures are made possible. For example, death at home may become a more realistic probability for more people as the NHS is redesigned around EOLC. Therefore it is important to remember that whilst 'choice' within EOLC policy explicitly refers to patient preferences, the way the notion of choice is used to mobilise services allows for an impact beyond the individual.

From an anthropological perspective, what is interesting about 'choice' in the context of English EOLC is not necessarily what people choose, but that 'choice' is seen as an object and means of care and how this is done. In this chapter I have shown how 'choice' and ACP create certain ways of thinking about 'end of life' patients, that positions them as reflective, autonomous individuals even if their preferences are influenced by past experiences, policy, and the documents in which 'choice' is documented. In this way, both the patient and their choice is 'constructed' in that the meaning and ability to act on these decisions is generated through healthcare, policy and social context that privileges thinking about and acting on the future. Whilst I have shown how 'choice' can be influenced, thereby questioning the focus on its authenticity, the main issue is that 'choice' is used as a mobiliser for organising services to provide care for the 'dying'. In the next chapter, I will explore how 'choice' is

done within clinical settings, further untangling the way in which it is negotiated and acted

upon as an object.

Chapter 5: End-of-Life Care Choice as Work

5.1: Introduction

'Choice' is a central element to current end-of-life care (EOLC) within England, constructing patients as reflective, future-oriented individuals even if the preferences they may 'choose' are influenced by past experiences and the tools used to enable advance care planning (ACP) as outlined in the previous chapter. Since ACP is one of the key mechanisms for improving the quality of the dying experience and service provision it is not surprising that the tasks involved in doing ACP are now part of a healthcare professional's repertoire. Indeed, vast amounts of money and time are annually spent on "up-skilling" staff about end-of-life care, ACP conversations and related documentation involving specialised training to enable them to be able to do and feel confident about EOLC. During my observations, much of this 'work' was done by nursing staff regardless of clinical setting as they claimed to be "the team members with the most patient contact" and self-identified their positions as one of liaising between services, implying they were best positioned to not only talk to patients but to do the formal documentation and communication within the system. This can be seen an extension of nurses' work within palliative care where they often deal with the dying (see Bailey *et al*. 2011; Clark 2000). This chapter explores how "doing choice" – the process of advance care planning from talking to patients to fulfilling service requirements based on this choice – is turned into work, and the consequences this has for the nurse-patient interaction.

Work is a heavily connoted term within the social sciences, encompassing politico-economic structures, power dynamics, and notions of embodied labour.[57] From an analytical perspective, the notion of work is beneficial as it implies transformative action and purpose. Rather than engaging with debates about what work is, or if the following descriptions are indeed 'work' in a sociological sense, I use the term to reflect the way the process of 'doing choice' in practice was discussed by informants in the many settings I encountered. In this sense, the term work is being employed both emically and etically to demonstrate how 'choice' has become a task, part of professional identity, and a way to make sense of the activity that is advance care planning.

In the previous chapter, I demonstrated how the content of documents like the Preferred Priorities of Care (PPC) structure and influence what is considered to be 'choice' in the context of end of life. Prior has suggested that in order to analyse documents, one must not only look at their content but also how they function in practice and the effects they have (2003). I therefore explore in several of the accounts in this chapter how the PPC and related documents are mobilised, or not, within end-of-life care nursing practice and how in turn this affects the kind of interactions nurses have with patients and their colleagues. In this way, these documents are more than just 'tools' to enable communication; they transform the ways in which nurses think about and do their work. Importantly, I illustrate the ways in which 'doing choice' is interpreted by staff as a way of demonstrating their professionalism and care.

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[57] See for example: Strangleman and Warren (2008) for a general overview; Durkheim (1997) and Weber (2003) for discussions of structural aspects, and Kasmir and Carbonella (2008) for an interpretation of experience in relation to structural elements. Acker (1990) and Twigg *et al.* (2011) discuss gendered elements of work and labour, the latter focusing particularly on embodied experiences of work in health and social care.

5.2: Locating 'choice' as part of nurse work

As the PPC and related tools have been "rolled out" nationally since the EOLC Strategy in 2008, I came across a dual sense of wanting to incorporate these documents into daily nursing practice, particularly for community district nurses, specialist nurses and in care homes. The first part is tied to a belief that using the tools (as designed or for their underlying value) will make care (and dying) better, both for the individual patient but also more generally for the public and for those caring for the dying. The second drive to use the tools is a (self) expectation that it should be used – they are designed and promoted as "best practice" and refusal to use them equates to rejecting what is 'known' to be best for patients on a national level. Together these motivations locate 'doing choice' as part of care and professional responsibility. In this section, I explore how nurses talked about this new "duty" and how through the formal process of documenting choice, the task of 'choice work' becomes one of many auditable jobs that nurses are involved in that demonstrate the care they provide.

In a conversation about her job, a specialist nurse explained how her role was to accompany dying patients on "their journey". Part of this involved talking to patients about their views, and "offering them choice", as well as "helping them to get there". What can be understood as the process of advance care planning – talking to patients about their preferences and managing services to realise those preferences – was therefore framed as part of her "duty of care to my patients". As such, it was not only part of her job as a nurse – one of the many tasks she had to do – but also an integral part of the relationship and interaction she had with patients. By framing 'doing choice' as a duty, the act of engaging with patients about their preferences is imbued with moral importance that reflected the

quality of the relationship, and consequently care provided. In this way, nurses expressed how the practices of advance care planning were part of their caring role for patients.

Beside policy makers, the group of people in this research most supportive of advance care planning tools, such as the PPC, were district nurses (although there was variation in enthusiasm and frequency of use amongst this group depending on personal and structural differences). These nurses regularly visit patients in their homes to dress wounds or administer medication, check current "levels of need", and record changes in the presentation of a condition. They often described their work as "task-based" and during visits a considerable amount of their time was spent updating paper and electronic patient records, even to the level of documenting that they had washed their hands. Whilst "out in the community" their interaction with patients may be relatively unmonitored and informal compared to clinic visits; the focus on paperwork and fixed, discrete actions positioned their role as a professional one in the patient's home. Documentation and formulating practices and interactions with patients as "tasks" is a way that district nurses make sense of their professional selves and roles.

Emily, a district nurse who had previously specialised in end-of-life care, was particularly wedded to doing ACP with her patients using as many EOLC tools as possible including the PPC. She felt these provided her a "way in" with patients that could launch "the [EOLC] conversation". During observations, I watched as she systematically worked through the form and she was resolute that the results of these conversations should be recorded by healthcare professionals and discussed by clinicians to regularly review patient care. She was the driving force in her surgery for implementing EOLC tools. Having recently returned to district nursing, which she liked as it was "more tasked-based than being a specialist

nurse", she broke down the process of ACP into discrete tasks to be completed at different stages, only one of which involved talking to the patient directly. Through this she created ACP not only as a series of tasks to be done as 'work' but also set it up in terms of obligations between herself and others, which related to or around the patient and described what "being a good palliative care nurse" meant for her. Overall, the introduction of the PPC into her workload was an extension of both her as a nurse and her usual work: a sentiment shared by many of her colleagues and peers.

The notion that these care plans are part of 'work' and protocol was also evident in the care homes I frequently visited. The information typically recorded in a PPC was part of the "service user care plans" the care home held on each resident. The section covering death was explicitly broader than a PPC is as it could include preferred place of death, any special last requests, and funeral wishes. When I reviewed Albert's care plan, I noticed that it was relatively blank, stating he "did not wish to talk to staff about the issue". This statement was repeated in all the plans made for him during the course of the study. We had had several conversations about how he imagined his death; when I asked him why he did not have similar conversations with the staff he told me he would if the questions were asked as part of a longer conversation like ours. Instead, "these things" (referring to the paperwork of the plans) often occurred all at once, discussing issues from his toileting needs to EOLC preferences, which was rather confusing for him. For a man with mild dementia and trust issues, asking about his personal preferences and thoughts about death as part of a tick-box exercise did not help him "open up". Whilst for Albert this approach to ACP "did not work", for others it is the launching point to a 'good death' (see section 4.2). Nonetheless, as this

example illustrates, for some ACP was not always part of an in-depth conversation about people's views but rather a matter of procedure lead by professionals.

Much like other aspects of ACP, the aim of having these plans is to ensure that the preferences are met. Such plans are often reviewed by the care quality commission[58] when determining the standard and appropriateness of care provided by a service. Yet, at least in the case of Albert, the lack of detail in his plan raises questions about the care home's ability to meet his preferences. Whilst the process may be patient-centred, approaching it as a task that relies on quick, open answers from the patient (or service user) highlights how these plans focus more on the outcome than the patient. Through documentation and record keeping, care plans demonstrate the actions done by staff and serve to symbolise care and imply practices that in theory will lead to a 'good death' (referring back to the EOLC pathway). The presence of these records is therefore important as a marker of care, but they do not necessarily reflect the conversations and interactions that lead to them.

Both within the community nursing teams and the care homes plans were regularly reviewed. This auditing of records served as a way to track the work staff were doing, if they were talking to the patients and documenting these conversations, and if they were following through with the actions such discussions may trigger. Audits within healthcare can serve to monitor staff, and help staff monitor their own behaviour, whilst also aiding staff in the ability to complete new tasks (Strathern 2000a; Strathern 2000b:4). In this way, ACP tools like the PPC serve as an audit tool by developing and displaying competency.[59] Consequently, not only has choice work been taken up as part of the nurse's work, it has been transformed into a moral duty and obligation to themselves, their patients, and their

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[58] The care quality commission independently regulates health and social care in England.
[59] This active function of the document was present in its design.

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employers, and in doing choice work through a task-based approach complete with documentation, the ability to talk to patients about their end-of-life care choices has become a practice that can be monitored.

5.3: Negotiating the parameters of choice work as professional practice

The previous section outlines how "doing choice", from engaging with patients about their preferences to documenting these in care plans, is seen and acted up on as part of nursing work. However, even with the audit element and an understanding that ACP is "best practice", during my fieldwork ACP was repeatedly absent or done in ways that did not focus on choice but rather symptom management. This was often in encounters with specialist nurses both in community and hospital settings, including palliative care nurses. Rather than approaching "end-of-life care choices" as something to be presented to all patients, these nurses navigated the conditions, physical environments, and people they were working with to determine when and what kind of 'choice work' was most appropriate. The work in doing choice, as outlined below, was therefore evidenced in these negotiations.

Many of the people I spoke to had never seen a PPC document or had the kinds of conversations EOLC policy advocates, even if the clinical staff involved in their care were positive about the purpose and practice of ACP more generally. At first it seems paradoxical that staff would 'choose' not to do ACP with patients even if they knew it was "best practice", generally supported the idea and viewed it as a hallmark of good care and enabler of good death. Rather than see this as a disjuncture between discourse and practice, I interpret the lack of ACP in these cases as a way of demonstrating their role as caring

nurses. In doing so, they are foregrounding values other than autonomous choice and as such, the work around choice is as much about negotiating the spaces and times to do choice work as it is about engaging the patient with their future death.

With several of the specialist nurses I met, including those focusing on respiratory and neurological conditions, there was more of an emphasis on symptom management rather than 'patient choice' per se. During observations and our conversations, the focus was on bodily changes, treating symptoms, and educating patients on medications. When I asked why more explicit modes of ACP and 'doing choice' were not used, I was told that doing so could "take away hope…take away from what they can enjoy now". Many staff noted that patients tend not to like thinking about the future, foreseeing a decline they know will happen after witnessing friends die of or with the same condition. Rather than exercise control over dying through choice, the emphasis was on living now with some knowledge of what to do next about the changing body. Planning for the future was secondary to "living now", and was therefore limited to being prepared for changes rather than imaging ideal scenarios to then be accommodated by the health services. Moreover, they did not view the lack of ACP involving patient choice as necessarily leading to something other than a 'good death'; they felt that if they could help their patients "enjoy the now" that their dying "could still be good". Through this, these nurses were emphasising values focusing on a different form of personhood – being active and seen as living – rather than choice. Not only does this deviate from EOLC discourse about the importance of patient choice and planning, but reframes how death, dying and living can be understood.

Yet, this does not mean these nurses did not like the organisational structure that ACP can provide. Shelia, a respiratory nurse, found the prompts of the "surprise question" and

documents a useful way to think about what she was "doing for [her] patients", whom she

saw "from diagnosis, or referral, to death" although patients came in and out of her care

depending on how unwell/well they are. When it came to talking about the prognosis and

death with her patients though, she found the tools lacked the ability to describe the likely

"ups and downs" they would experience from repeat hospitalisation, especially as each

exacerbation may be their last but with no way to know in advance which one that would

be. Instead, discussing treatment options, such as the availability of home oxygen, provided

a more tangible way of talking about the future than the more open topic of 'choice' at the

end of life. The uncertainty of the conditions her patients suffered from made advance care

planning impractical and optimistic. Since ACP relies on an imagined future that can include

dying at home, scenarios of unpredictable hospitalisation and sudden death are difficult to

accommodate within this framework. Instead staff navigate how to approach the future in a

way that allowed for practical action but did not necessarily focus on 'patient choice' as the

primary objective. 'Choice' about EOLC is narrowed down to care management, and the

process of dying is left as something that is unknowable (and therefore perhaps not

controllable through choice) as changes in one's condition are treated as incremental. By

focusing on responding to changes in need and working through treatment options, staff

are able to accommodate the shifts in patients' conditions and future uncertainties into

moments of action that could still be labelled as 'care planning'. In this way, the restricting

of 'choice work' allowed them to prioritize what they viewed as practical tasks rather than

abstract aspects of their work.

Staff also navigated the landscape of care planning by deciding when, how, and with

whom to do ACP with. This was particularly noticeable in terms of who they used the PPC

form with. By describing the actions and conversations of a specialist palliative care nurse I shadowed in a large hospital, I will demonstrate how navigating the hospital environment and patients is part of the 'choice work' nurses do. This reflects the complex context in which this work is done in, which is not evident in the policy discourse. "Best practice" was therefore reinterpreted to mean identifying which patients were suitable for approaching and completing the form. The largest element of 'the work' in this, for these nurses, was not in getting patients to complete the form but correctly identifying suitable patients as well as the time and place to talk to them.

The palliative care teams had previously carried multiple copies of the PPC document during rounds and had attempted initiating "the conversation" with every patient referred to them, seeing 'doing choice' as part of their specialised role within the hospital. "We were carrying them around for nothing" Hannah told me when I asked why they no longer did this. This blanket approach was no longer deemed "appropriate" or the best use of their (staff and patient's) limited time in the hospital. Instead of attempting to complete one for each patient, nurses chose who to approach and when to do this. Before we left for our ward visits one day, Nora was identified as being "suitable" since she was settled in and her diagnosis was likely terminal; all the other patients were "new referrals" and the nurse did not wish to broach the topic during her first visit in which she establishes rapport. When we arrived on the bay though, Nora was surrounded by photographs and newspaper clippings from her past and engaged us in lengthy stories. Others on the ward peered over their magazines through the half-pulled curtains and Hannah's questions about the present or future were met with short replies or glossed over in favour of completing the latest tale. Soon the rest of the ward seemed as energized as Nora as more visitors and other nurses

filtered in to talk to the rest of the patients. Glancing at her watch, Hannah excused us and promised to visit the next day when Nora's daughter was due to be present. We moved on to "quickly meet the new referrals" and the PPC document remained untouched in Hannah's notes as we moved around the hospital.

The hospital is depicted as a space not appropriate for the type of 'work' the PPC requires; it is not private enough, patients may be too unwell or too well given the circumstances, or there may not be enough time because of the other work involved in the hospital for the serious conversations that may unravel under the guise of a PPC. Similarly, lack of overall time with patients, referring to short admissions, meant that the hospital staff often felt they lacked the level of rapport needed to complete the form. Lack of time and the physical space – not private or long enough – were mentioned as barriers to completing the three questions the form entails. The reasons appeared rehearsed and well known – this was not an unusual scenario.

Hannah talked about "respecting Nora's privacy"; respect rather than choice is the value that underpins the account. Hannah did not even attempt the questions about preferences, but did query into Nora's current understanding of her condition. Not receiving much of a response and in the presence of compelling stories complete with pictures, she let Nora digress into the past as she checked her watch. Indeed, there is a sense that the time pressures of seeing many patients was at odds with the time it may take to have the conversations a PPC document invites, in addition to the extra attention the palliative care staff try to provide their patients.

When I later asked Hannah about Nora and the lack of PPC despite her earlier intentions, she commented that:

"It just wasn't appropriate to talk about it today…she was so happy talking about the past. So funny. Maybe another day…but we often find we can't do it here [on the ward, in the hospital]. People are either not well enough or we don't have the time with them. We spent too long with Nora as it is. Maybe I'll try to do it tomorrow when her daughter is in - she wants to know about her mother's future care."

Patients are not necessarily viewed as uncooperative (as in Olson 2011), but as unsuitable within this context. Moreover the very setting in which they found patients was inconsistent with the type of interaction expected as part of choice work. Nurses make judgements about whether ACP should be done, without asking the patient if they would like to do it. These judgements are based on how they interpret the patient's behaviour and current conversation – comments are made about being "too happy" or "too unwell" to discuss the future. The ability to imagine future scenarios with the patient is contingent on the patient's present state of health, the patient-staff interaction and the setting they are in. A chatty patient in a busy ward – like Nora – is therefore not suitable to filling in the PPC, even though, when planning today's ward rounds, she was the only patient identified as being suitable for this type of activity. In situations like this, determining suitability to do ACP is not just about the rapport a nurse has with a patient, but also their current conditions and the context of their interaction. Navigating these spaces is about the 'work' nurses do in relating to patients, both in their engagements with them and in how they frame the patient (or their context) as suitable for planning.

For the specialist nurses, the work involved in advance care planning is not just about completing the forms, but about being able to correctly identify the patients who are most likely to be able to do it and to find and manage a time and space in which to do this in a

way that matches their views about the future and disease progression. This all serves to demonstrate the professional ability of the specialist nurses with their expert knowledge and ability to navigate 'choice' and the uncertainty, people and spaces this involves. Rather than focusing on the outcome – the answers written in the form – staff navigate and make decisions about who – and when – is suitable for choice work. In a way, one could argue they are limiting who has 'choice and voice' when it comes to EOLC. However, for the staff, they did not view it as limiting patient choice but actually focusing on their care and them as people – it was more important to listen to their stories than force them to fill in a form. Choice is therefore weighed against other values, such as respect, and competes with other practices and priorities such as symptom management. Being able to navigate the potential complexities of doing choice as part of their work, it is more than just a duty or task but an activity that enables them to display and execute their professional judgement.

5.4: The many faces of choice work in hospice day-therapy

The word 'work' was most frequently used in relation to care and choice in the hospices I visited. The multidisciplinary team (nurses, art therapists, physiotherapists, complimentary medicine therapists, healthcare assistants and occasionally consultants) not only saw advance care planning and related tools as work that they wanted to do in order to improve the dying experience, but also something they should do. Prior to the EOLC strategy, they were already documenting patient preferences, particularly around advance decisions about treatment refusal. For them operationally, the PPC was an extension of this work and required a new form to fill in. It created another task and it was in the hospice day-therapy that I saw the form most regularly used. Here, staff spoke of the PPC as "just another part of our work", situating it as part of the holistic treatment they provided, as well as referring to it as "work for the patients to do". The multiple ways in which 'doing choice' was framed as

'work' within the hospice setting allows me to explore how 'doing choice' is part of the clinical encounter focusing on the interaction between staff and patients in this process.

Day-therapy followed a similar routine each day. The morning began with staff discussing the recent patients and their "goals" for the next six to twelve weeks. These goals are described as the 'work' patients do when they are in day-therapy; although patients may attend to relax, staff frame relaxation as a goal/work for the patients to achieve while attending. The purpose for day-therapy, one consultant told me, is for this work to get done. For some patients, this even extends to "homework" – tasks they are asked to do when at home and to demonstrate to staff their progress, such as updates on how relaxation methods were used at home. Work within day-therapy therefore is not limited to the staff and for the staff, work involves facilitating and monitoring the patients' work and progress. As they move through the list of patients, they discuss what has been "achieved" with them and the note-taker ticks off the different tasks whilst adding new ones and assigning a staff member to them. Patients are formed as subjects to do work with and on.

There were a few occasions when they came across a patient who had failed to return their PPC document that was set as homework. Although the PPC is a patient-held document, the hospice preferred if patients returned the form for photocopying; this enabled them to record and share the patient's preferences. Staff may speculate about this "failure", noting how certain people can be "difficult",[60] and resolved to approach the patient that day as the PPC is one goal they set most patients. By seeing patients on a weekly basis over months, they set up the possibility for it to be a process but with the

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[60] Personal character was something the staff often used to explain why patients may have "failed" to do their homework, although it was rarely reason enough not to pursue the task of documenting their preference. The only reason provided for not pursing PPC with a particular patient was if they lacked the capacity to make informed decisions.

expectation that it will have an outcome – something documented that can be acted upon. Hospice staff site themselves in a unique position through this possibility of rapport and frequent contact, building on their reputation for holistic care. For the staff, achieving this 'goal' of 'doing choice' through the PPC is not only a goal for the patient, but an on-going goal for the staff as well.

Oscar was one such patient who had "failed to bring back his PPC". Diagnosed with a neurological condition typically accompanied by a short prognosis and with only two weeks left in the programme, the staff decided they would talk to him that day to ascertain his preferences. Otherwise it might be "too late". After moving Oscar to a more private part of the room, set apart from the circle of patients in electrical recliners, one of the nurses asked him if he remembered the blue form they gave him the other week. He admitted to having "not done anything" with it and she asked if they could talk about the same issues now, poised with the paperwork and pen in her hands ready to write his responses in the tiny spaces provided (see Image 10). She was not holding a PPC document but rather the hospice version of patient preferences with a space for preferred place of care and preferred place of death (PPD).[61] This is the form the hospice used when they recorded and shared the contents of a PPC document with other services. If he would have brought the PPC form in completed, she would have taken it to the staff room to copy and fax to other care services, pieces of information transformed onto other bits of paper and into the patient's notes. Since they could "no longer wait for him to bring it in" she attempted to record the answers directly onto these forms for their records. The need for this information appeared to trump his apparent lack of engagement with doing advance care

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[61] In the hospice, place of care and place of death were often used interchangeably as if they meant the same thing.

planning up until this point. This is particularly poignant as the hospice actively sought to share the information from patients' PPC with other services, often acting as the lead service to ascertain and distribute 'patient choice'. Failing to obtain this information would be akin to not doing their work and fulfilling their role within the wider healthcare system. Attending to patient choice – both in "finding out what a patient wants" and importantly "sharing this knowledge" – was a key part of how the hospice staff viewed their role in patient care.

Preferred place of care: .... Initial_____Date _____

Preferred place of death:.. Initial _____Date _____

Image 10: Enlarged photograph of the form used by the hospice. Staff are to initial and date the form.

Her focus on place was evident in their exchange. "You know how last time we were talking about where you might want to be in the future" she asked Oscar, prompting him to talk about his preferences for different care settings. He joked how hard it is to know the future but how he figured his wife would eventually "get sick of" him at home. Alluding to a previous fall, she asked "if you were to become unwell, would you want to go to the hospital?". "Who would?" he turned the question around before launching into a story about how the last time the hospital staff did not know how to deal with his condition and his wife had to be there every day, all day long. His comments about care homes were similar and the nurse asked again where he would like to be in the future. "Home, I guess" he finally said as she wrote this down. "And what about further down the line…", her words

trailed off, avoiding saying death or dying. Without answering her question he told how

they just filled in the pond at home so he would not fall into it and drown. She nodded as he

talked, trying to steer the conversation occasionally back to her question about his

preferred place of death, without ever asking about it directly. After twenty minutes, she

suggested he re-joined the group and thanked him for his time. As he sat down she placed a

star next to PPD and a noted that it would probably be home.[62] Nothing more was

mentioned about the form he had at home. With the hospice document recording his

preferences, the staff no longer needed his version of the PPC as it is presumed the answers

would match this conversation – the goal of identifying the patient's choice had been

achieved.

  Whilst the staff rarely explicitly talked of how they 'worked' to obtain these answers from

patients, it is evident in her conversation with Oscar that the nurse actively sought to elicit

very specific information from him and this is what was documented. She steered the

conversation back to her agenda several times. Although his response illustrated a variety of

issues in terms of his expectations about his future and engaging with notions of

deterioration – or lack thereof – the underlying concerns or reference points for his answer

are not documented. This did not mean they were forgotten as she later included a

condensed version of this information in his patient notes; however, this context was

frequently not shared beyond the hospice. Such information is not easily communicable, as

it is difficult to distil and replicate like the single word that 'home' is. Choice work in this

scenario is therefore about extracting and tailoring information to suit the practices and

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[62] Some readers may wonder if 'home' was "really his choice". For me, this is not the point here and I pick up
Oscar's story again in the next chapter. I wish to emphasise that what is listed as his preference is forged
through the practices in the hospice that require documenting a preference, and that discussions involving
advance care planning focus on place. 'Choice' is therefore negotiated through interaction and is what is later
acted upon, not solely what a patient 'wants'.

purposes of advance care planning within the hospice and the co-ordination of end-of-life care that it viewed as its central role.

I am not suggesting that these practices are subversive and not patient-centred. Rather I wish to illustrate how patients and nurses arrive at the answer of preferred place together in a negotiation as part of both of their work in day-therapy. Patients were familiar with staff filling in forms as they conversed about all aspects of their lives and feelings, and several commented to me how they felt it was "their part of the deal" to answer these questions in order to receive the attention of the hospice staff, which they liked. To arrive at the answer of 'home', questions about the future had to be asked multiple times thereby drawing out the length of the conversation. Oscar may not wish to be at home at all costs; his answers demonstrate that he was concerned about how it would be for his wife as well as himself. Moreover, during this session of day-therapy he enjoyed the one-to-one time with the nurse. When talking about places, the nurse never once mentioned that he could come to the hospice; similarly he did not ask about this and had never visited the in-patient unit. His answer of home was co-constructed by what is said and not said in this encounter, what options were implied in the persistent questioning and evident in his past experiences, in the time available to him. The work of doing choice is a co-created process of arriving at an answer suitable for the purposes of the task.

Their encounter could be read another way in that by focusing on place of care and death as 'choice', the nurse did not emotionally connect with Oscar although he was expressing vulnerability. In effect, one could argue that 'choice work' leaves relatively little room for the emotional labour that can come with end-of-life care as staff focus on practical implications of choice – such as paperwork and liaising with other services – rather than the

reasons behind those states preferences. Having witnessed numerous hours of patient-hospice staff interaction, and the backstage conversations of staff, it would be unfair to say they did not engage on an emotional or empathetic level with their patients. However, this connection could be bracketed out at times when specific tasks, such as the example above and typically involving paperwork, needed to be done. It is more than the forms dictating the work; the forms (dis)allow for different kinds of interactions with patients. Attending to filling out the PPC-related documents, nurses are able to focus on patients through their preferences and futures. In a job that often leads to burn out (Keidel 2002), having work that can enable some form of detachment, whilst still being valued as care through its associated patient-centred connotations, potentially preserves staffs' ability to emotionally engage with patients at other points of their treatment.

The focus on choice within the hospice, as goal for both staff and patients, may at first appear system or staff oriented. Patients were set 'doing choice' as part of their work in day-therapy or as "homework". Staff actively sought to pinpoint a patient's preference, even when patients did not fill in the PPC document, and to share this with their colleagues within the health services. Moreover, whilst choice work was being done, the intensity of emotional labour may appear less than at other points during the patient's care. Yet, the underlying reason for these interactions and position of 'choice' as a valued aspect of day-therapy is that it was believed to be an integral part of the service that patients could be provided with that would improve their experience and help them accept their forthcoming death as part of a holistic care model. With this description of choice work within the hospice, I demonstrated how 'doing choice' is not just about individual patients or the discourses and values behind choice; rather doing choice is a complex engagement and

disengagement between healthcare professionals and patients as they navigate current and future care and needs.

5.5: Discussion

In clinical and social care settings, advance care planning (ACP) was operationalized as determining a patient's choice, often through the use of the Preferred Priorities of Care (PPC) document. In the previous chapter, I outlined how individual choice is influenced by material objects, past experiences and affect; in this chapter, what is recognised as choice is an outcome of interaction between professionals and patients. Yet it is not just the interaction between two people but the institutional settings in which these activities take place in that also influences what 'choice' is known and how it is acted upon. Overall, the activity that resulted in documenting choice was framed as 'work' by the staff.

Firstly, it was framed as part of professional work, particularly for nurses, and an integral part of their job as well as the interactions they had with patients. For some, determining patient choice about their death was a duty, implying a moral obligation to their patients and to their job to know this information and to act upon it. As part of their work, staff did ACP through completing the paperwork – 'documenting choice' – that was part of many institutional systems as a way of monitoring that patient choice was being attended to. There was an organisational need to know patient preferences, not only to act upon them, but to document that policy was being followed. 'Choice' could therefore be audited through this documentation as the notes generated served to symbolise both the patient's preference and the staff-patient interaction which communicated and accommodated this preference. In essence, 'doing choice' could be represented as 'doing care'.

At the same time, the process in which knowing patient choice was possible was framed as a task. The notion of task not only creates a sense of necessity, but also suggests that it is a process that can be done regardless of who the patient is; patients and their choices are therefore interchangeable pieces of this work. Janssen *et al.* (2008) argue that care in modern medicine is "techno-procedural" and therefore it should not be surprising that 'choice' has become a task. However, for some nurses, 'doing choice' was complicated by the types of patients they encountered and the settings in which this was done. Therefore, rather than 'doing choice' with all patients as a matter of procedure, staff navigated the contexts in which they worked and interacted with patients to present 'doing choice' as an optimal activity rather than a necessity. Through this, they were also able to express that part of their work was managing different values – such as respect and dignity as well as choice – displaying their professional ability to be sensitive to patient needs, even if these are not explicitly expressed.

Choice work was not solely the domain of professionals, however, as the hospice example demonstrated. Doing the paperwork involved in ACP was also something patients were tasked with. In turn, not only must staff be reflexive about how to navigate the landscape of 'choice' but patients are also framed as active agents. This is an extension of the arguments made in the previous chapters about patients being reflexive individuals; with 'choice' being 'work' that they must do, it becomes a disciplining technique through which their subjectivity can be brought to the fore and be shared. Yet, in the way that choice is generated in the process of negotiation between staff and patients, one may question whether the preferences stated are actually the person's 'choice'.

Rather than question the validity of the answers, I wish to contend that it is how choice becomes known and is acted upon that is important for understanding how advance care planning shapes these interactions. In the examples I have provided, staff do not deliberate on what "may really be" a patient's preference, but act upon the information they have to ensure that services meet these preferences, or to demonstrate that such preferences may not be readily knowable given the situations in which patients are interacted with. Patient choice and the forms used in advance care planning, such as the PPC document, are not just about what the individual patient may want as they die but the clinical work that surrounds end-of-life care. Indeed, this work is part of their design and a feature that makes them accessible to audit. In this, I am not asserting that the primary function of 'choice work' is to fulfil the task rather than to engage with the patient about their preferences, but that these are not mutually exclusive activities since "audits do as much to construct definitions of quality and performance as to monitor them" (Power 1994:25). The patient-focus policy has implications for how staff, particularly nurses in these examples, relate to patients.

Mol (2008) has argued that health services modelled on choice may fail to provide care to patients as they shift the responsibility of disease management to the patient. Although patients may be expected to complete the PPC document, nurses still felt it was their responsibility to introduce the topic and form and to respond to it. Rather than pose choice and care as binary opposites, as the above examples illustrate, 'doing choice work' can be used as a mechanism to demonstrate 'care'. This is not only limited to the use of the documentations in audits. For instance, by committing to talk to patients about their preferences and to be able to determine when this would be most appropriate, staff were expressing their "caring disposition" towards their patients. For many of the nurses I spoke

to, this was an element of expressing compassion towards patients – in line with discussing choice as a duty – and rebuked the current concerns with the NHS that nurses no longer are caring.[63] 'Choice work' was therefore part of what it meant to care for end-of-life care patients.

Some readers may argue, however, that the examples outlined above do not demonstrate what they would understand to be 'care'. In particular, the focus on organisational needs over patient desires, such as the emphasis on completing documentation, may ignore the emotional elements of that interaction. In these situations, however, the nurses did not feel that they were being any less compassionate; in fact, some felt that the very act of taking the time to talk to patients demonstrated this value. This illustrates how complicated the concept of 'care' is, which is discussed further in the next chapter. Nonetheless, these examples show a dilemma faced by many of the nurses: to do the paperwork required of them as part of their job or to forge meaningful interactions and relationships with patients in the time that they have to do this. This is not always an either/or scenario but a difficulty faced by many given the relatively limited time they have to spend with patients and the organisational demands and policy pressure to complete advance care planning paperwork as part of "best practice". Moreover, by focusing on the processes of 'doing choice work', nurses are engaging in emotional labour in that they can display detached concern (Fox and Lief, 1963; James 1992). Being able to relate to patients, but disengage emotionally, is part of their therapeutic relationship (McQueen 2004) and developing the ability to do this is considered a vital aspect of professionalism (Cadge and Hammonds 2012). To take this one

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[63] Throughout the study period, public media frequently portrayed scandals within care homes and hospitals where patients were not shown compassion, dignity, or respect. According to the accounts there were many reasons for this, including increased paperwork for nursing staff, reduced staffing numbers, and a lack of training in compassionate values. See Campbell's (2013) article for an overview of the Mid Staffordshire scandal which symbolises these issues.

step further, if "entertaining the viewpoints of other beings is dangerous [as it] entails some degree of becoming the other" (Kohn 2007:7), elements of detachment resist the risky consequences that being 'fully engaged' with patients may involve. In this way, this discussion of 'choice work' has shifted the emphasis from the individual patient to the interpersonal context in which end-of-life care is enacted.

In fieldwork, I first came across the term 'work' when hospice staff spoke about the activities they and patients do. Here I have used it both emically – to reflect how they used it – and etically to engage with wider discussions about duty, audit, and labour. In doing so, 'choice work' is both an object and a process reflecting a wider tension in EOLC about event and process in framing death and dying. Similarly, patients are both subjects of choice work, in that they are expected to engage with the tasks, and objects of it. By framing choice as work, it transforms it from an abstract value to an object that can, and is, operationalised within practice; not only does the term 'do something', as theories of discourse presume, but people 'do something' with it.

'Choice' is not just work that has to be done but part of how health care professionals, and in particular nurses, frame their relationships to patients as one of care. It involves the discussion of preferences with patients and the documentation of these preferences along with the care plans to allow for such preferences to be optimally met. Additionally, doing choice work requires considering who is appropriate for these discussion and when and where they should take place, thereby displaying a level of professional judgment and management. Whilst there may be a policy and organisational emphasis on knowing patients' choices as they near the end of life, these examples demonstrate that the choices

known are forged through staff-patient interactions and represent the dynamics of care in

these settings.

The Ghosts of the Living

Late 2011

Today's interview was difficult – not necessarily in how it went or how I got on with her, but the content. I had the constant feeling that I was opening up raw wounds that had taken ages for her to heal, but she had invited me there and on reflection, I said very little to prompt any of the sharing. These thoughts don't make it any easier to deal with though. I can tell this because my great ambitions of writing notes this afternoon has been replaced by two hours of sitting numb. With only my tea and music to console me.

Again, the phrase – I carry the ghosts of the living – comes to me. Images of all those I have met through the course of this research flash before my eyes. And the dead, but really it is the living that are the heaviest. The continued writhing, twisting in the mortality that life presents. Tortures my soul, burns in my mind. And no amount of intellectualising this, theorising, can make it better. No amount of writing, talking, demonstrating, can cure the life people are living. Experiences have been created and transferred, they will never leave. Memories may fade but even if they disappear from the mind they are engrained in the soul, in the body, part of the person.

She really loved her husband and talking to me today was a part of demonstrating that love. Not only was his picture there between us, but his presence. Etched into almost every inch of the home. She said he wanted to die, and she supported that, as much as it hurt her to no longer have him next to her. But he's still there – I see that. I

felt that. The wanting to go but never fully departing reminds me of so many of my

interviews, particularly with those who are 'ill' or call themselves 'too old'. We leave

marks of our lives through the people we touch.
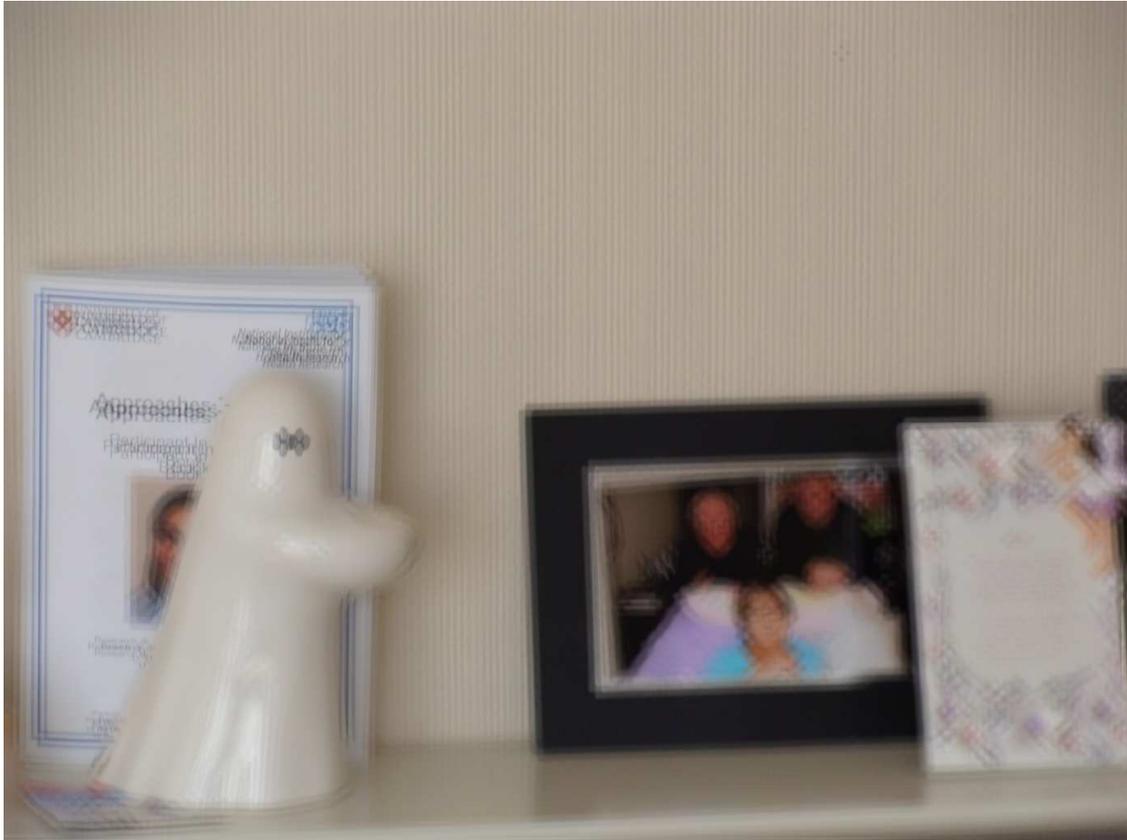
Image 11: Thinking of ghosts, death and the living reminded me of how I spotted the information booklet for this study next to the picture of a recently departed woman and a statue of a ghost, almost like a mini-shrine in the living room.

Part 3: Experiences of Living

Chapter 6: Family

6.1: Introduction

Chris sat across from me in the busy hospital, coffee cup in his hand. Since being ill and subsequently unemployed, his family have lost their home and were waiting for new social housing. Chris did not feel settled without a house, worried about failing to leave a secure family base before he died. Last time we met, Chris commented on how they might get a house quicker if their adult son moved out but Christ felt he could not ask him to do this. "I'm worried how it might affect his relationship with his mum in the long term – she needs him for support". He had commented before on how close the two were. "It's not about me", Chris said, "I have to think of the others and the longer term consequences".

Chris' remarks, whilst specific to his case in terms of finding a new home, resonated with many comments I heard during the study. Making plans for the future was not just a simple act of individualistic consideration, but involved considering what the consequences might be in the future for others, particularly when they themselves – like Chris – may no longer be there. Whilst the previous chapters illustrate how policy and health care practice and practitioners relate to 'patients' and create patienthood, this chapter focuses on how these patients – as people – relate to others that are part of their daily lives and thereby experience personhood. Rather than focus on choice or an autonomous essence, people can

be understood through the specific networks they participate in (Pyyhtinen and Tamminen 2011). In this study, people are embedded in social networks, the most noticeable being 'the family', and their position within and relation to other members influences the ways in which planning for the future takes place and is discussed. Unlike the emphasis on the individual and their preferences that is present in end-of-life care (EOLC) policy as illustrated in Chapter 4, these accounts demonstrate the very attached, entangled, and related nature in which people think of themselves. Consequently, 'choice' for those who may be categorised as 'end of life' is less about personal expression and more of a demonstration of 'being' within a social context.

This chapter places these people at the forefront telling stories of who they are. Since one's sense of who one is arises in and through the process of social interaction (Hockey and James 2003:157) and "social relations reveal the persons they produce" (Konrad 1998:645), it is possible to view who a person is through these interactions and how these relationships form them. Unlike individualism which premises singularity, the notion of 'person' implies relating (Strathern 2005) and for the people I spoke to relating to their family was a key element of who they were and how they portrayed and understood themselves. Being part of a family, even for those who had lost spouses or were estranged, was important to all the people that I spoke to. I purposely leave the term family vague here, however, as people used it to describe a wide variety of social arrangements from the nuclear family to extended relatives and family-friends. Nonetheless, what underlies all these definitions is an understanding that family is important to what it means to live a meaningful life for the people in this study. I explore being part of this social nexus by first describing how people remain embedded in the family and in their roles as parents. These

relationships are integral to their personhood and the flow of care and concern between

people is a way of demonstrating this. However, declining health and death present the

possibility of altering these relationships and a shrinking of their social network;

consequently emphasising and continuing bonds within the family is a way to enable

relating and personhood beyond physical deterioration of the body.

  Death presents this possibility of altering relationships because it disrupts the social order

and dislodges daily practices and roles (Bloch and Parry 1982). As discussed in Chapters 1 &

3, there may be a disjunction between the social recognition of death and the biological

death where the body ceases to function as it does in life. In particular, in Western contexts

there is a concern that people suffer from a social death before their bodies die, in that they

are treated as dead and socially excluded, and that this may become a predictor of

biological death (e.g. Sudnow 1967; Sweeting and Gilhooly 1992; Timmermans 1998;

Lawton 2000). In Chapter 3, I noted how English end-of-life care policy embodies a concern

about social death (as social exclusion and treating dying people like passive bodies) by

emphasising the individual. Here I explore how people and their families live in the presence

of death (as a result of a diagnosis of a life-limiting condition even if not formally labelled

end-of-life), and the possibility of changing social relations. Ultimately, the examples show

that relatedness is expressed through care and concern and in doing so these 'dying people'

maintain, and even strengthen, their roles within their families at a time when their very

position and existence may be otherwise questioned. Due to the ability of these

relationships to endure end of life, dying and death, this analysis undermines the

assumption that social death (when understood as social exclusion) occurs.

6.2: Children Come First

One of the most common topics of conversation during my visits with informants was their (adult) children. Along with comments about the weather and pleasantries as one arrives and departs, updates about their children flanked our conversations as well as being interspersed throughout our meetings. Remarks ranged from news about latest jobs, welcoming grandchildren, to worries about their children's love lives. The amount of talk about children, and the emphasis often placed on this talk in our conversations, established the informants as parents. In this way, they were demonstrating their familial ties (see Finch 2007). The emphasis placed on their continued role as parents, even with children who are now adults, may be seen to exaggerate and thus shore up their status as a person – one who is still connected. This occurs at a time when other social roles and networks – such as those provided through work – may have been lost; the family is thus a key site of interaction, relationships, and connection to a wider social world. Moreover, they displayed themselves as parents still concerned about their children's lives, and frequently it was revealed through discussions about the future, putting their children before themselves as they had perhaps always had done. This has an impact on how 'choice' can be conceptualised as it displaces the primacy of the individual – without a role other than to choose (Giddens 1991) – with a person who is entangled and embedded in a social world that may not always foreground their declining health.

Since they were parents, talking about their children was part of their role and did not seem abnormal, even if the initial purpose of the interviews was to discuss their own health and future. For example, Vera and Henry often spoke of career advancements of their children and grandchildren. Talk of their children demonstrated the continued relatedness they had and were part of. Our familiarity with each other as time went on meant such

revelations became both regular and less surprising, and demonstrates how I developed a connection with these people and how our relationship was one that they sought to sustain through continuous engagement.

During the course of the study, none of the people I spoke to regularly were in formal employment or had many social activities that did not in some way revolve around their health, including our visits. Often discussions with friends considered health issues as they had either made new friends through support groups or friends were, like themselves, "getting older". This can be indicative of their social world shrinking (Roscow 1973) and it is this change in role that is sometimes understood by policy-makers as social death (see Chapter 3). Interest in their children's lives could therefore be seen as one of the main ways they were connected to the outside world that did not directly concern or confront their own declining health. For example, Strathern comments how "…the mother has to see the child not only as an extension of herself but also an extension of the world" (2005:6) in a way that allows parents to come know the world and themselves. For example, Christina told of her children's love lives, providing a running commentary on what developments she approved, or more readily disapproved, of. In this way, people could extend their ideas and their influence into the future via their current relationships with others. Their children's successes in love and life, and the near misses, were a matter of great concern and worry, demonstrating a continued interest in their children's lives similar to the rest of their time as parents. This was particularly telling when we could easily spend 30 minutes talking about their children, filled with emotion, agitation and bodily movements, when discussions about their own life worries were limited in these senses or were quickly deferred to issues involving their family. Talking about their children allowed people to disengage from their

own issues and re-focus their concerns on life rather than death. What is important for people, and thereby what constitutes them and their values, was expressed through this focus on family. Whilst psychologists and clinicians might refer to such behaviour as denial (e.g. Rousseau 2003; Zimmerman 2004; Borgstrom *et al.* 2013), I contend that it is illustrative of the embeddedness in relations of people, how who they are and what matters in their life can be more than death and dying, and the investment parents have in their children's lives. Rather than death redefining who they were, talk of their children sustained their role and existing priorities, including expressing what gave their own lives value.

Barbara's relationship with her daughter illustrates this. In her 60s and widowed, she lived alone and managed her lung condition by herself. Barbara had occasional visits to the community clinic unless she felt too unwell in which case she would pull the emergency cord in her house and be whisked away to hospital. She often did not talk about all of her children, but one daughter, Jan, featured regularly in our discussions and exemplifies this investment, perhaps even at the cost of Barbara's own health. Jan was the closest child – both in proximity and regular contact with Barbara – and had recently become pregnant with her second child during a "cancer scare" of her own. Despite Barbara's declining health and frequent hospital stays, she often babysat for Jan wishing to help her out where she could. It was not uncommon for Barbara to have contact with Jan during our visits, and occasionally the baby was dropped off whilst I was there. "It's a good thing I'm better now so I can look after her" Barbara told me once after reflecting on the difficulties of her caring duties, struggling to lift the growing child. With the possibility of a second child, however, Barbara was unsure if she could safely continue regularly babysitting. When I asked her how

she might tell her daughter, she said she could not do that and hoped Jan "would just see I can't….but I doubt it… she has too much going on herself…". Barbara was resigned to helping out as long as she could as she had always been the family carer. "All my children are selfish like that…perhaps it's my fault, I raised them that way…always looking after them and putting them first…it's normal I guess". Through these discussions and continuing to babysit, Barbara maintained her role as a mother and grandmother, actively displaying the need Jan had for her. However, this does not come without a cost in that Barbara's own health and needs were left out of this relationship; yet it appeared as if this was something Barbara was willing to sacrifice in order to "be there" for her daughter and continue the family dynamics. Rather than accept a change or loss in role, Barbara side-lined her own health in order to maintain who she was – a caring mother – and this provided her with a sense of purpose.

  Barbara's comments illustrate how she continues to position herself as a caring mother in relation to her children, even willing to put their needs – in this case babysitting – before her own. Rather than push for her health to be the main determinant of family dynamics, she continued with 'daily practices' as much as possible. Barbara regularly rescheduled our visits to fit around the babysitting and her nurse told me she also did this with clinical visits. The only time she declined to babysit was when she was in the hospital – physically removed from her home and daily role; however, it was not unusual for the baby to be around a day or two after Barbara was discharged. What this example shows is how maintaining her role with in the family – as mother and grandmother – was something perpetuated by Barbara and her family even in the face of declining health. Barbara explains this through her past relationships with her children, where she put them first. These

relationships continue despite other changes in their lives that might challenge the ways of relating. By continuing her role, the care she provided for her daughter provided a constant in her life, which was changing due to her declining health and gave her something to look forward to which made her feel helpful. By maintaining her parent role, she is able to maintain who she is. Roles are actively negotiated, both in terms of relations to others and with respect to one's own health, and involve finding appropriate activities and spaces in which to express personhood.

Interestingly, Barbara's declining health did not change her relationships with some of her other children, one of whom she was estranged from. This was also the case with Albert, whose son refused to visit his father in the hospital or care home unless "absolutely necessary" and was even then noted to be absent. This may be contrary to the cultural narrative of death and adversary bringing families together.[64] Rather than suggest that they have already experienced a 'social death' in that they are excluded, the lack of social activity is a marker of the on-going relationships, even if of a different intensity, to their families and their enduring personhood. Nonetheless, both Barbara and Albert occasionally wished for the bonds to be renewed but were resigned that the current state of affairs reflected past actions (on both sides) and that this was likely to continue. When talking about the future, and what they may like to do before death, they both factored this estrangement into the equation. For Albert, he wished that he "could move back home – but I know he won't have me", referring to the family fallout that preceded his diagnosis, whilst Barbara told me she did not expect to hear from that child and would not pursue it, without specifying why.

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[64] Smalley (2010) suggests that struggles against a common enemy and tragedies bring people closer together. Dunn's (2011) play about home deaths illustrates how care for the dying can bring people together. Family systems theory posits that families grieve as a system, thereby effecting each other (Shapiro 2001), although this does not presume that it will bring them closer together.

Therefore, whilst the parents may put their children first, they also respected their children's distance. This was factored into decisions about the future and the ideal way of "passing on", both in the sense of dying and leaving a legacy within the family. What these examples show is that maintaining their parent role is not just about continuing with care duties, as Barbara does with Jan in the form of babysitting, but also respecting distance within the family. To suddenly adopt a new role would mark dying as a significant event and threaten the continuity that bonds can provide. This does not mean they do not mourn the kind of relationship they could have, but that they accept this as part of who they and their children are. This distance – or lack of intensity – is another element therefore of their personhood and collective family identity.

Talk of children is a way of maintaining a parent-child bond and roles at a time when these may otherwise be challenged due to changes in health, ability to carry out daily tasks, and discussions of death. Other research has suggested that such times may be "painful adaptational challenges" in familial relationships (Walsh and McGoldrick 1991:25), changing social relationships (e.g. Middleton 1982); social science and psychology literature tends to discuss this time as one of crises (Ellis 2012). Howarth (2000) has shown how dying people may actively seek to keep connections post-death through creating materials to be engaged with once they have departed. However, this family talk demonstrates how these bonds are still present and acted upon in a time of 'decline' and perhaps even after death. In most cases it was about maintaining relationships as they are rather than fabricating new ways of interacting. This could be interpreted as a way of negating changes in relationships that dying may present, maintaining the central role of a parent in the family. I would argue, however, that rather than being an active form of maintaining status, concern for children

and reflecting on how this may affect future interactions is part of what it is to be a parent and an integral part of their personhood. As Barbara says, "that is how I've always been with them". Continuing the way people relate to their children helps maintain continuity when other things, such as their bodies, may be changing.

6.3: Caring Relationships

In the previous section I illustrated how parents talk about children frequently and how relating to their children is a way to maintain their role as a parent and express their personhood through these connections. Underlying the talk about children, is a desire to continue to express care and concern for them and to be needed, or at least appreciated, as parents. Their care and concern demonstrates their relatedness. This section focuses on how the dual aspect of care and concern, as discussed and done by participants, flows in multiple directions within a family, beyond the parent-child relationship. I use the term flow here to represent the fluid movement of these elements and to note that whilst it transpired between people, it was not always reciprocal in terms of the kinds of actions people took. The term flow enables movement between scales, issues of agency, and emphasises interconnectedness and dynamism (Rockefeller 2011). The flow within families included where the 'dying individual' expresses and does 'care' for those around them rather than just being a recipient of care as they are traditionally portrayed within healthcare policy and literature (see Part 2). Moreover, this exchange of care and concern has implications for how one thinks about choice and care, and the kinds of choices people make with respect to their own lives and death.

I use the phrase "care and concern" here to emphasise that caring is not just an act but also an emotional state and way of relating to others, and can come in various forms. These

two terms imply one another, therefore when I use just one of them in the descriptions, the other is implicitly present. In this way I am drawing on older literature that talked of both caring for and caring about another (Graham 1983) but am not limiting care to be something primarily expressed by women; although the care I write about is predominantly within a family context. Moreover, in the descriptions it can occasionally be unclear who the care-giver is and who is the care-receiver in the exchange; this is because people can be both simultaneously. The issue is less of who is doing what and the potential imbalances of this, but rather to demonstrate that people are more than just passive receivers of care and that they reconfigure their roles and future lives in response not only to the care and concern they receive but the kind they wish to (continue to) provide. In this way, the mutual relatedness engendered by care and concern blurs the boundaries of who needs care and who provides it, as both are distributed across and between people. This is different from how healthcare positions people, with an emphasis on categories (see Chapter 3), and suggests that the daily experience of living with illness (and dying) within the family is not one of being a passive recipient of care or active agent of choice (as in Chapter 4) but a more diffused manner of subject-making.

  To illustrate the flow of care and concern, and how it modifies 'decisions' and action, I will use the following description about Rosalind and her daughter Sara. Close to 100 years old, Rosalind "complained" of general health issues "related to [her] age" – poor eyesight and hearing, general feeling of frailty and increasing sense of inability and lack of motivation to do tasks for herself. She felt she had "lived too long" and was "ready to die" asking me to "praise the Lord and clap" when she did. Rosalind described herself as "being a burden" on her daughter, and she tried to do things herself that would reduce this burden; her motto

was "it's not my right to impose". This included completing the crossword Sara enlarged and left for her each morning, to demonstrate that she was "keeping up her side of the deal". Rosalind did not want her "difficult character" to be adding extra burden on Sara – the only 'legitimate' claim to her time was through physical need. The notion of being a burden is not new (e.g. Barry 1995; Grunfeld *et al.* 2004) but is often cast in terms of the tasks or activities one requires of another (Thomas 1993); however Rosalind's manner illustrates that this can include non-physical tasks and emotional states. By completing the crossword, for example, Rosalind expressed her appreciation for Sara's concern and this formed a kind of reciprocity for Sara's time and caring duties. There are expectations of care and of how one provides and accepts this, expectations of others and the self in these interactions that serve to moderate how care and concern are expressed within their relationship.

  Sara regularly visited, making the four-hour round trip to see her on the weekends. Following Sara's divorce, she suggested that Rosalind move closer to her in a new retirement home. Here Rosalind could continue to "be independent" but the reduced distance would make "popping around" easier. Sara realised her mother's condition "would likely decline over the coming years" and "wanted to be able to help her". This example problematizes the ways of relating set out earlier in this chapter that discusses how parents attempt to maintain a particular directionality of concern from parent to child. Here it is the child who is actively seeking to care for and expresses concern for their parent. Care can be considered to be the quality of relationship between people, extending the idea that it is the nature of a relationship (see Thomas 1993) and by moving her mother closer Sara could enhance their relationship and sense of connectedness.

Appreciating her daughter's visits and recognising that as a grandmother herself, Sara was busy and stressed without the added hassle of long drives, Rosalind moved. As a mother she continued to exhibit concern for her daughter. "I did it for her…I wouldn't have moved if it was just me…but she has a life and I can't blame her", Rosalind said one day as she reminisced about the "old days back home" before the move. Since her husband died over a decade ago and most of her friends had "gone anyway" Rosalind further rationalised the move. Yet Rosalind also wanted to be closer to her daughter to continue their visits. Through concern for each other and themselves, Rosalind and Sara both made changes to their lives and daily routines through the physical positioning of Rosalind. Rosalind explains this as her wishing to reduce the burden on her daughter, and expression of concern and gratitude, and Sara as one of care and concern for her mother's well-being. Care and concern therefore not only binds people but can shape what they do, including where they are.

When Rosalind's condition deteriorated, in that she no longer regularly got up for breakfast, Sara employed "home help" in the morning to supplement her own daily visits. During the week Sara was on holiday with her children and grandchildren, Rosalind did not leave her flat, instead opting for "quiet meals" on her own. Upon her return, Sara was worried by this "development" and decided that moving her mother to a care home would enable her to "feel more involved and be more active". For Sara it was important to see her mother engaged in "life and not wither away"; Rosalind felt comfortable with her current withdrawal saying "at my age what can you expect?". This indicates that people have different expectations and these play out in how they express their care and concern, both for others and for themselves. After weeks of hunting, Sara found a care home with garden

access, something Rosalind liked about her retirement home, which at this point she had only lived in for less than two years. Again, not wanting to be an extra burden on her daughter, and to appease her daughter's desires, Rosalind moved. Subsequently, what Rosalind did and where she was reflected how her daughter cared for her – moving her mother to a care home was not an abdication of her caring responsibilities but demonstrated the concern she had for her mother's well-being and personhood. This has implications for how care homes are typically viewed within England, as my informants told me, as places where people are 'left'. Instead they can be viewed as spaces that embody a particular negotiation of relatedness that is not equivalent to abandonment. Although the move represented a change, their disposition to sustain their relationship remained constant. Sara's concern and willingness to move her mother shows a desire to continue to interact with her as a living person, maintaining both her own sense of self as her daughter and her mother's ability to be who she is by "keeping active". In this way, personhood is enacted through relationships, roles, and activities that symbolise their interaction even in the face of bodily decline and changes in location.

Similarly, in my interviews I came across multiple couples – rather than parent-child dyads – who had decided to move because of the 'needs' of one of them, even if they both would have preferred to stay in their 'home'. Considering family dynamics, and the need for compromise, such actions and statements are not surprising. Rosalind died in the care home. The reason I choose to highlight this is that in the context of current end-of-life care, such compromises in family – and care – arrangements demonstrate how choice over place of care is not necessarily an individual preference as demonstrated in Chapters 4 & 5. Rather where someone is cared for, and ultimately dies, is a consequence of the

relationships they are part of, including the caring relationships. Therefore place is more indicative of nuanced relationship dynamics, with their compromises and expressions of mutual care and concern, than independent choice.

Location is an expression of who a person is – not necessarily in that the characteristics of the place represent a personality (Dyck 1998; for comments on how the home represents emotional and ontological security see Gurney and Means 1993). Location reflects the connections a person has and the networks they are embedded in. Where one 'is' positioned, both physically and socially, is a result of these relationships. For Rosalind, her moves illustrate the relationship she has with her daughter. Her move to be closer was to remain connected to her daughter, to be with her family even if not 'at home' anymore. Choice of place therefore is not necessarily about where one feels most comfortable but where one feels most connected and cared for. In terms of end-of-life choice policy, rather than focus on the physical setting of care and death (see Chapter 3) the focus could be on how a place reaffirms and alters a person's connections and how this impacts their relationships, both in terms of who cares for them but also the care and concern they can display.

These arrangements might arise from or give way to a sense of being 'a burden'. Other research has shown that perceiving oneself as a burden is a major concern for those with long-term conditions and in end of life; it is more of a concern than place of care (Waghorn *et al.* 2011). The concept of burden was used by people to describe instances where they felt the "demands" they required from others exceeded what could reasonably be expected within that relationship and/or what extended beyond what they could return. Care and concern is therefore deeply embedded in the relationship, rather than serving only as an

interaction. Whilst Rosalind wished to be less of a burden so that her daughter could "live her own life", several of the people I met were concerned with how the care demands they placed on their family members, as a consequence of their condition which were phrased as in addition to what caring tasks and concern were typically expected within the family, was detrimental to the health of these people. The worry was that their spouse, for example, was sacrificing their own health and quality of life in order to support them. In these cases, as with Rosalind, people would moderate their behaviour to lessen the perceived burden. By doing so, they expressed concern for others and therefore where also care-givers as well as being care-receivers.

For example, Oscar commented on how he had tried not to complain for years to his wife if something was "not quite the way" he would like it, although he acknowledged "that she knows me well and does her best". Unable to move much of his upper body due to a progressive neurological condition, his mobility and agility were restricted. Perceptions of burden therefore moderate what preferences are expressed, including how and when they are made known, if ever. In the context of end-of-life care this has implications for what people feel they can legitimately claim as their preference – such as dying at home – if they express their concern for others who may have to care for them in such a situation.

Such considerations are not unheard of, although this was more often expressed in discussions about the future than what was documented in people's advance care plans. In the case of Oscar, his care, and caring relationship with his wife, directly related to his "end-of-life care choices". When asked by the hospice, Oscar said he would like to stay at home (see the description of this exchange in Section 5.4). When Pamela had a shoulder operation, Oscar moved to a care home for a fortnight. Within hours, however, both

"discovered that despite locating the only suitable care home" in the area, the staff were ill-equipped to meet his needs. Despite the difficulty, Pamela made the trek by bus to the care home to make sure he was being looked after and had what he needed, including food and drink. They describe similar experiences when he was in hospital and consequently they were "convinced" that "Oscar staying home is best for us". What could be an expression of 'individual choice' about comfort was one of shared benefit and accountability. This decision addressed his care needs and preferences surrounding them, as well as his concerns for how his care elsewhere does not necessarily "make life easier" for Pamela. By stating that the decision is best for "us", both of them are positioned as active agents in his care planning.

What is "best" for the couple becomes what is expressed as "best" for Oscar (the individual) when spoken about at the hospice. Yet there are different values underlying these definitions of "best"; in the first instance it is about the interaction of care whereas in the second it is about acknowledging his dignity. Although such decisions are often viewed as 'rational', even in this case as Oscar spoke at length about how care in other settings was unsuitable, the decision is also emotional as it is bound up in their mutual concern for each other. What is therefore taken to be an individual's preference is actually a decision forged through past experiences, concerns and considerations of multiple persons. If persons can be considered dividual – understood as being "frequently constructed as the plural and composite site of the relationships that produce them" (Strathern 1988:13) – their choices can embody this dividual nature. Choice therefore reflects the constructive nature of people's lives and relationships, where care, need, and even persons are distributed as well as being informed by emotional factors in addition to practical issues.

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Whilst such decisions may reflect a jointly held preference about care and family arrangements, it nonetheless places the spouse as the primary carer. Within end-of-life care policy and practice, there is an implicit notion that family can be (and perhaps should be) the locus of caring. Although decisions perhaps reduce burden on their family members, by reducing travelling for example, the same people may experience senses of guilt and fear related to their care and concern for their loved ones. Once it was known that Oscar wanted to stay at home and even die at home, Pamela began to raise concerns about her ability to cope even though she had "managed well" until now with the help of adaptations to their home and attending a support group. Caring comes with responsibility and is not cost-free both in economic and emotional terms. She worried about the potential guilt she would have if she "couldn't cope and called an ambulance…what if he died in the hospital because of me?". Caring for him up to his death seemed reasonable, and something she wanted to do as his wife, but at the time of death, she felt her ability might change, whether this is due to the actual tasks required or how she would emotionally react to watching him die. She was worried that this inability would reflect (or be judged by others as) a lack of care or love, which is not what she felt. Whilst she supported their decision for him to remain at home, this 'choice' was not without consequences and underlying apprehensions for how it may turn out. There was not only the burden to decide where he should be cared for, but the consequences of that decision in that he, the tasks of care, and the guilt she felt could be considered 'burdensome'. Sense of guilt indicates that choices have consequences and that people take responsibility through concern and care. Sharing the choice to die at home also distributes the responsibility, even if not the burden, between the couple. Expressing concerns about being unable to cope is one way of demonstrating the burden and responsibility that accompanies such choices about care.

As with Rosalind, Oscar's location reflected the connection he had and the caring relationship he was part of. Yet in the practice of end-of-life care, as demonstrated in previous chapters, choice is often expressed as something external to the individual and detached from the context in which it is formed. Oscar also disperses the choice beyond himself by saying it is "our choice". In both these ways, there is an accepted detachment of the decision from the 'individual' person and locates it within a wider social space. Whilst the first form of detachment may seem dehumanising by stripping away context despite its intentions, the latter example illustrates how detachment from the self allows for choice to be an expression of multiple persons, and thereby accommodating Oscar's connection to his wife. For Pamela, the practicalities of this decision allow her to continue caring responsibilities, including concern for her ability to cope. In this way, choice is a shared expression of their relationship and the care and concern that flows between them.

Hastrup (2010, 2013) uses the notion of 'entanglement' to describe how notions of nature and society are engaged within climate change research and anthropological studies of such phenomena. In doing so, she highlights that they do not just 'interact' but are intertwined with one another in ways that are more than just casual. Here I wish to borrow this term as it reflects how people become persons through mutual relatedness. The descriptions of the flow of care and concern imply more than just interactions where objects may be exchanged. Expressions of and receiving care and concern are a way of binding and creating persons. It embeds people further in a web of connections – people are entangled in each other's lives. Actions, discussions of action, and 'choice' reproduce and reflect this entanglement. Rather than assume that individuals are detached from others, and that their choices are therefore equally 'individual', the examples above illustrate the dividual and

distributed nature of both. The following section carries on with this analysis and explores how boundaries, such as what category a person comes under, are blurred by this flow.

6.4 Blurring Roles

As an illustration of how care and concern can flow through and across multiple relationships beyond a dyad and can shape what daily life looks like for the people who I met, the following descriptions demonstrate how difficult it can be to articulate the complexity of care and concern. It illustrates that such exchanges are not necessarily reciprocal, time-bound or easy to articulate. Instead, the layers through which these elements are weaved in everyday life, practices and talk demonstrate how they permeate existence. What it means to be part of this couple, larger family, and a person within these units of relating is shown through the ways in which concern is expressed. The focus is therefore less on what care is and more on how expressions of care and concern illuminate relations and thereby persons.

As with many of the couples I met through the course of the study, one person was presented as the 'patient' – the person with health concerns that were more immediate and continuous – and the other as the partner or 'carer' as the healthcare professionals would categorise them. This second person was positioned in a role related to the first, for a 'carer' cannot exist without someone to care for or to take care of. In our initial meetings couples would often present this dynamic to me, the carer talking of the practical aspects that needed to be considered, how their caring role affected them (often expressed when the other person was out of the room), and how they anticipated future changes. The 'patient' was left at liberty to discuss other issues and frequently were the ones who talked about daily news, non-health issues, or their ambition to keep on living in spite of these 'care

needs'. They were often the jokers, making light-hearted conversation in the same space of all the care talk. These encounters mimicked what I witnessed in clinical shadowing, how the same couples and others interacted with health professionals. Being a patient or carer therefore was something that was an identity and role they presented and performed, and was determined by relationships.

It was only during the course of our visits, sometimes after months, that this double-act faded away and the 'patient-carer' dynamic became more complex. In the case of the Wards, both in their 70s, Alfred was wheel-chair bound as a consequence of his progressive neurological disease that led to increasing immobility. He required considerable help to complete tasks that he would have otherwise done for himself, such as getting up in the morning and dressing. His wife Gail was his primary carer since the onset of his condition over 10 years previously. Only after several conversations did I discover that several years ago Gail was diagnosed and treated for cancer and was regularly receiving medication because of this. Although whenever we discussed their calendar it was always filled with medical appointments for Alfred or social visits the couple had planned – her health treatment was relatively hidden in most of the exchanges. In this way they did not position Gail as someone who was a (formal) receiver of care; yet, at the same time they positioned Alfred as someone who could both be in receipt of care but also active in other ways.

Despite the surprising absence of medical appointments in the calendar for Gail, this did not mean her health was not an issue for the couple. Gail was responsible for most of the household tasks, as well as Alfred's personal care. During our visits she made us all drinks, placing Alfred's with a straw in a location she knew he could easily access by bending his head or holding it for him. Additionally, she classified herself as a "worrier" and frequently

became anxious about his condition, often not wishing to talk about potential decline.

Alfred was therefore concerned that she was "overworked" and did not adequately look after herself since she always placed others before herself. Although he appreciated her care, he frequently joked that he would "prefer a blonde Swede". Even though this offended Gail, the underlying message of the jest was that such a change would enable his wife to relax more. He encouraged her to hire help, such as a woman who did their ironing, and for Gail to continue to be part of her group of friends and meet them regularly. More recently, this extended to encouraging Gail to go on week-long holidays without Alfred as a form of "respite and recovery". This meant that Alfred's personal care would have to be performed by others during these periods; their sons devised a rota to accommodate this, one even traveling from Spain for a few days, for they too felt their mother needed time not as a 'carer'. Nonetheless, before these trips Gail pre-prepared meals so "the boys have something to eat", maintaining her role, presence, and expression of care even when physically absent from the house. This example illustrates how multiple people congruently express and exchange concern and care for each other, and the nature of these expressions illustrates the Ward family dynamics.

Gail felt that she expressed her love through food and eating was more important to the couple now than ever before as Alfred's condition meant that soon he would be unable to consume solids. Friends and family, however, were less impressed by the extents Gail would go to in preparing food, especially for dinner parties. On one occasion, all the invited guests insisted that Gail do no cooking and they would each bring a dish. She found this difficult to manage as her usual hosting skills and way of inviting people into her home was thwarted by the very people she wished to share the evening with. During these events, Gail was

simultaneously a care-giver and a care-receiver, and she found the combination of roles and the directionally of the care she received difficult to navigate. By discussing the concerns of friends, and how Gail managed – or not – to appease their concerns demonstrates how these caring relationships may extend beyond what is traditionally understood as 'the family' (i.e. the nuclear family; e.g. Sussman 1959; Jamieson *et al.* 2006). Nonetheless, the impact of the concern is that it shapes the home/family environment; in this case, how Gail entertains is modified by her friends' concerns about being overworked and Gail's concern to be seen to listen to them even if this meant changing her preferred behaviour and way of interacting with them.

Her friends, many who had similar life experiences to the Wards, consistently reminded her that she must look after herself, not just Alfred: "I have had lectures from several friends that I try to do too much and that the body can't cope with it all." This was quite difficult for her to do as she frequently side-lined her own health to prioritise his needs and care for him. Not only was this exemplified by the absence of her 'condition' in previous conversations and the calendar, but also in that she would comment that "I am so willing to work hard and make life good for Alfred". Only later, after being severely ill herself for several weeks did she "take these concerns to heart" and realise the "physical limitations" of her body. During this time the son and daughter-in-law that lived locally helped both Alfred and Gail. The Wards began to reorganise their lives so that Gail could do less but "still be there" for Alfred. What this example overall shows is that the roles of 'care-giver' and 'care-receiver' are not as clear and bounded as they are often portrayed, particularly when the matter of concern is involved. Concern breaks down the dualism of traditional concept of care. Gail is at once both, and by being the subject of other's care and concern, her role

as Alfred's 'carer' is challenged as she comes to terms with the implications of others' concern.

What Gail could do – and therefore who she was – was not only challenged by her health but by how others reacted to her health and apparent lack of concern for herself. One's role can therefore be said to be created, sustained, and changed through one's relationships with others, not only in the care one provides but also in the concern and care one is subject of. This position, which challenges the dualism of care-giver and care-receiver models, is what all persons are since they are always subject of other's concerns as well as being concerned for others. Unlike EOLC policy that sets out patienthood through the roles of the patient and health professional, in people's everyday lives such categories become blurred through the mutual exchange of care.

Yet in order for Gail to be an active recipient of these elements, others – namely their children and friends – had to come in and be more active in the daily tasks of living. However, this did not negate her role as Alfred's wife and how she positioned herself in relation to him as one of concern. More generally, this extended example illustrates how people try to organise and structure the patterns of daily living. Such structure serves to reinforce roles and the network of care and concern they are part of. Yet, in the face of increasing frailty and illness, as well as the concern expressed by others, there are moments when patterns change; however, by maintaining key positions – such as being the mother and host – people can hold onto particular identities and ways of relating.

Care and concern is an expression of the relationships people are in and illustrates family dynamics, particularly in how the dualism of care-giver and care-receiver does not fully account for the movement of concern between persons. Through illustrating these

relationships, descriptions of care and concern also show how they shape who a person is and what is done. The above examples demonstrate how care can flow not only from parent to child but also the other way around as well as extending and involving other people including friends, and how such flows and reactions to care are indicative of the quality of relationships between people. Moreover, people have been shown to modify what they do, say and even where they live to reflect the care and concern they have for others and the relationships they are embedded in. Similarly, the care and concern one is subject to and is part of shapes the person and their roles. This can impact what end-of-life care policy considers 'individual choice' or preference in that if the person is a reflection of their relationships, then the choices expressed are an extension of this and reflect the network one is part of. Individual choice is therefore a misnomer as what is expressed and acted on is entangled in a web of affect and relations.

6.5 Discussion

The purpose of this chapter was to demonstrate how persons appear in the nexus of social relations rather than conceptually as individuals as presented in Section 4.1. The family is one of these, and a key one for the people I spoke to. These relations can be articulated, or made visible, through the flow of care and concern that entangles people in inter-relations where they are both the agent and subject of these acts, elements, and emotions. Such an approach challenges static or singular notions of the 'carer', for example, as one can be both a care-giver and care-receiver at the same time.

Dealing with aspects of reciprocity was an underlying theme in the examples, and giving is often conceived as part of kinship (see Carsten 1995). On a basic level, reciprocity is an exchange between two persons or groups, and if balanced the transfer is considered equal

(Sahlins 1972). Often the term is used to describe economic or gift systems (Mauss 1990), where relative values can be applied to objects. Reciprocity in the examples here is of a different sort where people are exchanging care and concern for each other, and such tasks and emotions are not readily quantifiable. However, people have a sense of the balance of their relationship – relative to how it typically is – and it is in this context that 'burden' is understood. There are certain expectations of others and of the self based on their roles and how they have interacted in the past. These expectations and considerations for the other can cause people to moderate their own actions, including the 'choices' they articulate, and the concern they express.

Being able to continue to fulfil one's reciprocal role within a relationship is not only important for maintaining the connection but also the sense of self, as personhood is informed by the relationships one is part of. Inter-subjectivity is part of one's own becoming and being (see Toren 2002). By maintaining connections and playing an active role in the lives of others, a person remains socially grounded and part of the family. At a time when other connections may be changing, due to declining health for example, the intensity of relating to family members may shore up one's identity and personhood despite the possibility of change. Changes, including changes in relationships, have significant consequences for understanding the self. Therefore maintaining relationships is a way of maintaining the self.

Lastly, being part of a family with its own flow of care and concern highlights their relational role and that these people are still part of a wider social system. Such accounts do not support a thesis of social death based on exclusion and the curtailing of relationships and identities. Instead, even when there were changes to one's role, by maintaining a sense

of entanglement and concern for others, people could sustain other aspects of their identity. This also extends to the image of the home, which rather than being considered the desired place to be, reflects the nexus of relations a person is in and wishes to continue to be part of. Home is therefore about people and not place.

The examples in this chapter illustrate how people's own experiences of everyday life, with the backdrop of declining health, are focused around relationships and being part of their wider family network. Rather than emphasising their individual preferences and plans for the future, as EOLC policy does (see Chapters 3 &4), they shape their activities and concerns in the context of others. This suggests that 'choice' may not necessarily be located within the individual but through the relations a person is part of. Understanding who they are personally is about understanding the relationships they are part of and that are important to them, and how they interact with other people. The next chapter further elaborates on the daily experiences of persons in this wider context and how relating to others and to the self can be challenged by a temporal notion of the life-span.

Chapter 7: Endings and Waiting

7.1: Introduction

In this dissertation, I have been dealing with death and dying through the lens of English end-of-life care (EOLC). As the dualism death and dying points to both an event and the process leading up to it, the phrase 'end of life' holds this double meaning and it is this duplicity that I seek to address in this chapter. Throughout the fieldwork there was a sense that there may be certain endings through experiencing death and finishing fieldwork, and as the EOLC policy suggest, a linear passage of time with notable decline. Yet, such moments were difficult to locate. Due to their health conditions, all long-term research participants could have, at some point or another during the study, been classified as 'end of life' according to policy guidelines. Yet many of them outlived the period of fieldwork, as well as the category of 'end of life', as they were still alive over 12 months after the end of data collection. This chapter takes the paradox of living beyond 'the end' as its central theme in order to explore how elusive endings were when one takes a relational perspective and to describe the sense and embodied nature of waiting many people encountered during this on-going process. Consequently, the encounters with waiting and attempting disengagement do not readily match the policy's pathway approach to death and dying.

In the first section, I address the possibility that through death and deliberate action to disengage with other persons relationships can change and possibly end. Whilst the previous chapter stressed the importance of remaining connected as a way of sustaining personhood, this section explores how the intensity of relationships can shift as a result of

events, like death, and processes of grieving. 'Endings', and seeking them, is a metaphor for detachment in this chapter. In examples of family members in bereavement and professionals seeking to conceptualise the ending of relationships with patients, I illustrate how what may be viewed as a discrete event is actually an on-going negotiation. This has consequences for understanding the self, role and the relationships one was part of. Through this I challenge the simplistic categories that EOLC and research has created (as discussed in Part 2) and to temper the notion of easily severed relationships.

For me, the problem of creating endings was a consequence of the longevity of many of the research participants. For many, no 'active dying' or even decline was present during the course of the study and they did not frequently engage with advance care planning. I was left wondering, what is going on if people are not experiencing the various kinds of deaths the literature and EOLC policy had described. In the preceding chapter I describe how people are actively still part of their family networks, commenting on how this is part of 'living'. Another aspect of their experiences that featured prominently in our discussions was the element of 'waiting', marked by a sense of inertia and uncertainty despite the rhetoric of pathways, trajectories and awareness. Waiting was also something I personally experienced through the research period and caring for my grandmother in 2012. Through a discussion of how waiting is, I explore whether it is indeed a special liminal period or rather similar to other aspects of life as people move through daily activities marked by past experiences and future possibilities.

Together with Chapter 6, the descriptions and discussion in this chapter emphasises people's experiences and how they make sense of their lives and interactions. Unlike the constructing nature of EOLC policy and practice in Part 2, where persons are understood

within the remit of patienthood, the interactions and experiences drawn on in Part 3

illustrate how personhood and experiencing life are not necessarily limited to or by a

biomedical framework. Not only are persons connected and made up of their relations with

others, but they sense and make sense of their worlds in a multitude of ways beyond the

rationality implied in individual-focused configurations personhood. Discussions of

detachment and waiting contribute to this understanding by illustrating how people make

sense of who they are by relating to the social world around them and interacting in it.

I have purposely placed 'endings' before discussions of waiting as this breaks the temporal

order of the process-event continuum. Firstly, it is because 'endings' were expected and it

was only through their apparent absence that the action and activity of on-going

relationships and time were confronted. Waiting, rather than preceding 'endings' only

became present when 'endings' were missing and in this sense, 'endings' precluded the

waiting I later describe. Secondly, in the discussion, I question the temporal order attributed

to waiting if it is considered a liminal period. By placing 'endings' before this period of

waiting, I signify how I reject this consideration due to the lack of clear transitions in and out

of this phase. Cumulatively, rather than suggest 'end' is an event, the descriptions lead to a

more fluid understanding of endings, signifying an on-going negotiation of relating.

Unpicking waiting challenges the simplistic notion of endings and through this I contest

the notion that dying provides the 'endings' – detachment – that death implies and that

knowledge about death makes the transition from living to dead more transparent. Instead,

the theme of relationality bears through and waiting can be viewed as a form of being. This

has implications for the construction of 'end of life' as a distinct period that can be

successfully navigated as implied by EOLC policy; instead the experiences of confronting

waiting and incomplete endings illustrate the less than straight-forward nature of 'end of life'.

7.2: Endings on the Horizon

As described in the previous chapter, people try to actively maintain their relationships, particularly with family members, even as their health declines and threatens to jeopardise their sense of self and their social position. The ability to maintain relationships within the family was through the active negotiation of roles and expressions of care and concern. Such evidence rejects a simplistic notion of 'social death' where people are treated as if they were dead before they have physically died, and that maintaining personal connections is an integral part of their personhood. In this section, I engage with scenarios where relationships with a dying or dead person may change due to death or active disengagement of one person from the other to explore how, when and to what effect or extent this occurs. In this way, I am addressing the anthropology of detachment (see Candea 2010) although I ultimately suggest that detachment in terms of severing relationships is not completely possible. Rather than an 'end' being in sight, the descriptions below highlight how changing relations are negotiated by those that remain and how doing so shifts the focus of relating from one of connecting to another to one of considering the self.

7.2.1: Detachment through Death?

Death and dying provide an opportunity for relationships to change as a person is removed from daily social activities (e.g. Froggatt 2001). Rosalind, who was nearing 100 years old, felt she had lived too long and wished to die. Indeed she claimed to be "waiting to die". Although the medical staff involved in her care expected her to die "at some point", her death was not deemed to be imminent and her family treated her as if "she could go on

living for years". As part of their yearly trip to the United Kingdom, her extended family visited her one afternoon. We all sat basking in the sun at the care home as her great-grandchildren played in the grass. As the afternoon drew to a close, they left with no great fan-fare just a few hugs and kisses and promise to see her again when they were next there. Rosalind thanked them for visiting. When I spoke to her privately after they had left, she told me that she had said her "good-byes", even if they had not realised it. Although they were not flying for another few days, and could potentially visit again before they departed, Rosalind was content that they had been and wished that they would enjoy the rest of their trip without worrying about her. Two days later they flew back, without any additional visits to the care home, and within a week of the afternoon with the family Rosalind died.

In some respects, Rosalind had withdrawn herself from the family after this afternoon by not wishing to see them again during this current visit to England. Looking back, it seems almost obvious that she 'knew' she would die soon and never see them again. In some respects, it appears as though she was able to find a resolution to these family connections by saying good-bye. Yet, during the week leading up to her death, although most of her family did not physically visit the care home, they often spoke to her on the phone and her daughter was often by her bed. After she died, all the family were able to attend or view her funeral over Skype. Rather than signify a disconnection between them, after she said her good-byes, the way others could relate to her were altered although they continued to be in touch. Her dying and subsequent death did not severe the relationships others had with her, although they limited her ability to relate to them. Rather than create an 'end' through detachment, death shifted the ways of relationality within the family.

Another example of when death did not provide the clear severance of connections comes from Mable's son, Matthew. I had met him when I visited her in the hospital and he was active in securing the equipment and social care needed for her to be discharged home. As no suitable night nurse could be provided, Mable was admitted to a care home where she died less than three days later, acting "completely out of character the day before she died". When I spoke to Matthew a few months after his mother's death, he told me how he often thought that they would have "more time together" and was frustrated as he had done all he could to "push" the plans along for home care. Although he said that with time this "upset" had faded, his mother was neither out of his life or his thoughts as he continued to engage with her and their past. Immediately after her death he cleared out her house – "it took on a sort of intensity" – but several months later it still sat waiting to be sold and he regularly visited to tend to the garden she loved. Looking back he regretted the urgency with which he cleared out her house, but hoped that such actions would help his grief, drawing on popular models of grieving (see Kübler-Ross 1969; Rando 1988). Death and the events following death are alluded to as possible solutions to the pain felt upon "losing a loved on". There is the assumption that they may provide an end, a way of closing off the relationship with the deceased.

Yet, despite these actions, "it is all still alive" he said, referring to his mother and her life, as he waited for her house to be sold, scattered her ashes, and awaited the arrival of a headstone (which was delayed and not due to arrive until seven months after her death). Rather than her death rupturing his relationship with her and the cleaning of her house symbolically removing her from his life, even after death Mable was still an active agent with whom he regularly interacted with. Relating endured even if the form of the

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relationship had changed. Some have argued that managing the death of others is about managing the shift in relationships post-death (e.g. Bowlby 1980; Arnason 2007) and empirical studies suggest that relationships continue and evolve after death (see Howarth 2000; Kellehear 2007b; Palgi and Abramovitch 1984). Yet, it is not just his mother as a person that he continues to relate to, but 'her life'. Here personhood is extended beyond the body and a set length of time to represent the entirety of their experiences and relationships. There are shared memories, personal possessions, and ritual markers that symbolise both the person and their life and it is these that are able to supplant the person in the relationship. Not only were relationships an important part of Mable's personhood, but they formed and continued to inform Matthew's personhood. Despite dying, her ability to be part of him remained. In this way, the quality of the relationship changes in that the objects of relating shift, and the intensity of the relationship may alter because of this and through time as memories fade and objects are lost. Nonetheless, rather than death presenting an end to relationality, it extends beyond living and incorporates 'the life' into the connections people have with one another.

Similar to Matthew, I have found that the relationships developed 'in life' continue 'after death'. For those that had died, I had presumed that after I completed the interviews with their family members and associated health-professionals, my relationship with them (the now dead person) would end. However, during the course of the past year, I have found this not to be the case and the continuation of relationships, albeit of a different kind and intensity, has been evident in the interviews I conducted. Additionally, I continue to absorb myself with the stories people have told me, reflect on our interactions, and engage with 'knowing them' – exploring what they were like, what they could have meant when they

philosophised about life, and how what I have learnt will be carried with me. I am not

asserting that a relationship developed during research is equivalent to the parent-child

bond; instead the parallel that I am drawing is that that relating to persons does not end

with their deaths. The connections developed with people extend beyond their lives, as well

as beyond fieldwork – again a blurring of previously boundaries imagined through research

practices and social interactions (see Chapter 2 and Part 2). Instead of suggesting death as a

way to 'detach' or breaking relationships, it is more fruitful to explore how it changes the

ways of relating and the intensity of relating. In this way, people remain entangled and

personhood continues to be experienced through one's interactions with others.

In these cases, there is a form of continued remembrance that extends beyond the time-

frame usually allotted to 'grief', which in the UK is considered to subside after the memorial

as indicated by the short, two day statutory leave period allowed following bereavement.

On one level this remembrance resembles engaging with who the person was – a memory

of them. On another level, it is about imagining what else could have been there, exploring

new avenues to how things between persons could have been. Moreover, particularly in

Matthew's account, this continued engagement with the person who has died is not just

about memories but about concern, extending the exchange beyond death, not necessarily

about how she is now in any possible afterlife, but how he could have done things

differently to express the concern he still feels and is encountered with as he interacts with

material objects that symbolise her and her life, such as her garden. In this way

relationships continue but the way concern flows is different to when both people are

'alive'. Death therefore is not a complete cut off of the relationship and grief and

memorialisation alone do not account for how relating continues. Interest in others, and how this relates to the self, is sustained in the period after death connections remain.

7.2.2: Shifts in relating and cultivating detachment

Through these examples it is evident how death is on one hand imagined as a possible moment of breaking relationships and on the other hand, presents people with a shift in relating rather than a complete severance. This applies to both definitions of biological and social death because even if the person is treated differently, there is nonetheless an element of interaction. Being dead or treated as dead is not the same as not being part of meaningful relationships, even if the on-going interactions appear one-sided. In this section, I continue with the idea of disconnecting as a one-sided activity. For the purposes of simplicity, consider the above examples as ones where it is the dying or dead person that has 'acted' to break the relationship through their dying. In the following examples, these are contrasted with instances where those who have been actively engaged in interactions with such persons seek to extricate themselves from the relationship on 'professional' grounds and the difficulty they have encountered in doing so.

The first scenario of sought disconnection arose from witnessing Coleen, a specialist community palliative care nurse, retire and how she and her patients responded to this. As she "wrapped up her job" she took on fewer "cases" as "her patients" died to minimise the number of patients that would have to be transferred between nurses. However, not all of her patients had died by the time of her retirement, and many grieved the "loss" of her, apprehensive as to whether they could develop the same kind of relationship with a new nurse. She was clearly an important part of their lives, but rather than focus on how her patients reacted to this, Coleen's struggle to understand and fully disentangle herself from

these relationships illustrates the complex nature of connections even towards the end of life.

Coleen had decided to retire after many years as a specialist nurse to spend more time with her family and to focus on her own health. She phrased these as "lessons learnt" through her work, and whilst she relished the ability to help people "prepare for their deaths and make the most of their lives", she felt that overall she was "giving too much" of herself to do this. She wanted to realign her life to relationships and activities that mattered to her beyond her role as a nurse – to frame her understanding of herself and her personhood. In order to do this, she felt she needed to make a "clean break" from her previous job. Her sense of self was tied closely to what she did, and her story shows that people can actively shape personhood and pursue meaning through the relationships and activities they wish to be part of.

As part of retiring, Coleen had to pass on her "caseload" of patients onto another nurse. As a professional, she was deemed to relate to these people as patients, and construct them as persons through the care she provided them, particularly in enabling them to experience 'good deaths' – this is similar to the descriptions of work in Chapter 5. Her professional role as a specialist nurse entailed visiting them regularly, talking about their desires and fears, and being with them in times of intense vulnerability. Although she viewed her interactions with 'patients' ultimately as a "job", she admitted there were certain people she had developed a personal rapport with that extended beyond the nurse-patient relationship. She attributed this to the ability to understand "who they are" through their conversations and these shared moments. In essence, there were people she "liked" and "became buddies with". Such attachments were deemed to be beyond the remit of her job. She had

developed a level of concern for people that went beyond the care she provided as a professional and beyond framing them within the remit of patienthood. Whilst she anticipated that her colleagues would view the continuation of relationships as "professionally inappropriate", without death to "naturally" break the relationships before her retirement, Coleen could not envision the disengagement that retirement implied. The transition from being their nurse, with a "legitimate" reason to be part of their lives, to being someone who could remain in a relationship with them despite no longer being in this role seemed to be an unclear and uneasy transition.

Relationships developed in one context – the patient-nurse setting – therefore can bubble over into other aspects of people's lives through the affect they generate. However, in doing so, they become problematic as they cross boundaries of understood ways of relating. Continuing interacting in roles other than nurse and patient extends beyond the categories that professionalism erects. Whilst these distinctions may function during the set period of visitations – in the clinical encounters so to speak – the qualities of the relationships developed in these interactions can blur these boundaries. Coleen was no longer a 'nurse' and these people were no longer her 'patients' but it was unclear if they could be friends and if such an arrangement would enable them to continue to interact. There was also the sense that this continued interaction would endure until death; however, as the previous examples demonstrated, even death does not provide a simple solution to the entangled nature of relations. Although one may wish to disengage from relationships to other persons, this is not an easy or straightforward process due to the concern that has developed over previous encounters. Rather than a simple end, 'endings' of relationships are unfolding and projected into the future with no clear closure.

For me, ending fieldwork brought on similar tensions as many informants were still alive and well and I lived in the area in which I conducted fieldwork. The traditional model of ethnographic fieldwork in a foreign land creates a notion of distance between researcher-in-the-field and the relationships they are part of, and researcher-at-the-desk or at home, although several have commented on how globalisation and electronic communications are challenging this distance (e.g. Simpson 2009). The presumed distance created by ending fieldwork in the forms of active data collection was not readily replicated in this study as the field site was local – there was no significant change between 'fieldwork' and 'writing' other than stopping visits. I felt therefore that the break distance would have otherwise have generated needed to be created in order to move on to the next phase of the research.

Firstly, I attempted this by visiting less frequently or for shorter periods, thereby changing the intensity of our interactions. Yet, when the "last visit" came, many people requested that I continue to stopover and keep them updated on the progress of the study. Some even suggested I had become their "friend". Even a year after fieldwork ended, it was not usual for me to hear from some of them. The continued communications distort the ability of distance – both physical and metaphorical – to end our relationship and as Glowczewski *et al.* note, fieldwork is a "never-ending endeavour" (2013:121). Nonetheless, the kind of relationship we have has changed over this time. I was unsure when and how the transition from researcher to friend had occurred and what this new role obligated. Most of our encounters had focused solely on them without the usual give-and-take exchange of a friendship; they knew relatively little about me beyond what I presented to them as a researcher. Conducting fieldwork is a performance (Castaneda 2006) and there is a constant juggle of distance and intimacy (Hume and Mulcock 2004) and yet there had been in shift in

our relationship through time. I do not have the space to dissect this changes here; the purpose of this example is to illustrate how although I sought to extricate myself from the relationships, I was unable to do so 'successfully' as the demands created through the engagement I had with them during the study meant that who I was, from their perspective, had changed. I had developed the connections as part of the fieldwork since ethnography rests on the relationships one builds (Wind 2008); however I had become more than 'a researcher' to be seen as someone who could be a friend and had displayed an interest in and concern for them. Although the official 'end' of the data collection has meant a shift in our interactions (in that I am no longer actively studying them), it had not managed to create a permanent 'end' to our interactions.

Both Coleen's and my example problematize the notion that relationships with people, developed in a 'professional' context come to an automatic end when that role – as nurse or researcher – is abandoned. Detachment through distance, change of role, and halting of professional activities could not be fully achieved as concern for people developed beyond professional capacity. By doing this, the boundary between professional and person, in one's own life and sense of experience, is distorted. Since these relationships formed part of our subject-making, the sense of an objective distinction, and the straightforwardness of 'ending relationships' is problematic. In essence, how one understands themselves is through interactions with others and the realisation that relationships are uneasy to become disentangled from, and how such attempts create unease, underlines the importance of social connectedness for personhood. Moreover, the desire for continued interaction on both sides indicates that people like to be part of caring relationships and do not wish for these to end.

Whilst relationships are important to establishing and maintaining roles, as I argued in the previous chapter, they also extend beyond role-creation and maintenance to inform personhood and sense of self. The way this is done may be different for the participant/patient and researcher/professional as the former sought to maintain these connections in order to maintain a pattern of interaction and be part of a (dwindling) set of relationships. For many, they expressed how these interactions were important for them in being able to openly talk about themselves in ways that they could not with family members. They could claim the professional as a 'friend' who was not vested in familial dynamics, and therefore the decisions that went with these. Yet, for the professional, this shift in ways of relating brought questions about what their new role was vis-à-vis the relationship – can one be 'friends' with previous 'patients' or does this break professional boundaries?[65] Being able to maintain, and break, relationships on one's own terms is a new way to establish social boundaries and exert a sense of agency in the creation of selfhood and an understanding of personhood. This is done at a time when many of the relationships that formed and informed one's role are subject to change. Consequently, personhood and an understanding of the self are forged through interactions with other people and an important aspect of this is being part of caring relationships, either in expressing or receiving care and concern.

Although I speak of a change in the relationality, this does not imply that there is a clear transition from relating during one's life and relating after death, or indeed based on the earlier examples, relating as part of professional interaction and continuing contact after

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[65] Both Coleen and I had colleagues who viewed continued interaction beyond our professional roles as inappropriate. This is an example of how categories inform the way people are to relate to one another. A different approach, which Coleen particularly embodied, is that we care for people sometimes regardless of our professional role, and respecting them as persons requires continuing bonds in a way that enables this care and concern to be expressed.

these roles have been relinquished. Matthew found that whilst his mother was in the hospital, he did certain things like order a new bed for her home and visited her more frequently than he would normally do. This pattern of 'other activity' trailed further once she was discharged, and then later in terms of organising her funeral and the selling of her house. Whilst these actions were spurred by events, there was an element of fluidity in how his relating to his mother changed over time. Similarly, in terms of ending fieldwork, I paced our visits differently, called less often, and took longer to reply to standard correspondence after fieldwork ended. This extended transition, coupled with the fluidity in which these changes occur, make it difficult to locate where the possible 'ends' may be. Changes in interaction and death are not as transformative, in terms of creating completely new selves independent of the other, as others have implied (c.f. Kübler-Ross 1969, Worden 1991). This is because personhood is constituted through relationships; instead of breaking relationships death alters the intensity of them thereby not completely removing all remnants of the other person.

This section discussed how 'ends' are sought, or anticipated, through changes in relating brought about by shifts in professional roles and through death, but how 'endings' are themselves elusive due to the fluidity and extended nature of concern. Most importantly, death itself does not serve as an ultimate tool of detachment; rather it may spur changes in the intensity and ways of relating, but such changes can also occur during 'life'. Whilst in Chapter 6 I stressed how continuing the flow of concern was a way of maintaining social roles within the family, here I have discussed how flows of concern may challenge the categorisation of such roles, particularly within the professional context in that a 'patient' or 'participant' can also be a 'person', as can a 'nurse' and a 'researcher'. This furthers the

point made that categorisations are useful in particular contexts in informing the ways

people can be related to (see Chapter 3) but also seemingly arbitrary when attempting to

explain other experiences that go beyond these categories. By challenging the rigidity of

these roles, categories, and forms of relationships by exploring how concern continues

through death and dying, I emphasise how one relates to others not only through their

roles, but inter-subjectively. It is here that concern is developed, continues, and connects

even after 'endings' are presented.

   Earlier I made the distinction between the previous examples and these latter examples in

terms of the directionality and responsibility for initiating ending relationships, suggesting

that they can be unilateral. In the examples, the unmaking of relationships was not

reciprocal. People continued to request and engage in interaction even if an 'end' was

presented to them. The agency of one person to end a relationship could be complicated by

the demands made by others, either explicitly or implicitly. With particular reference to the

idea of care and concern, that the connections they generate continue in spite of attempts

to disentangle indicates that interactions are not always balanced or fully within 'rational'

control. Instead engaging with others creates affective demands that can span beyond

boundaries and time.

   Up until now, the argument has been that relationships are integral to understanding

personhood and one's self. Yet, relationships can change in their intensity and this change

has the ability to undermine these understandings. Change does not equate to

disconnection, as the above examples illustrate. People are never fully disconnected, even

after death, as they continue to be part of how other people relate to themselves. The idea

that personhood is founded on social connections remains. In terms of the self, by

maintaining connections, even if in thought if not in interaction, and element of previous

embodied roles remains and continues to inform the self. Endings therefore are not 'the

end' and do not threaten personhood and selfhood in the way disconnection may imply.

Detachment, or attempts at it, therefore, is both a process as well as an event mirroring

descriptions of death and dying in Part 2. It is a presumed event that coincides with other

occurrences – such as death or retirement. Yet the way it was experienced, particularly the

lack of it in complete terms, indicates that it is felt as a process. For some, this is an on-going

process with the hopes or notion that it may one day come to closure. In the meantime,

people wait. This notion of waiting can be further extended to how people, who were

potentially facing 'end of life', experienced their every day. The enduring nature of this wait

and relationships has implications for how 'endings' can possibly be understood – they

present a mirage and orientation but were not realised within this study.

7.3. Waiting

'Waiting' – often depicted as an odd mix of inertia and "living each day as it comes" –

appeared in almost all my interview notes. However, it only became a prominent feature of

my work after my own experience of 'waiting' when caring for my ailing grandmother.

There was something profound in feeling 'waiting' – and for me the frustration that came

with it and not knowing how to understand it – that made it more accessible for analytical

interrogation. Previously, I had naively assumed that those who expressed that they were

waiting were ultimately waiting for decline and death, following the linear pathway model

of EOLC. This passivity, however, could not account for the agency and activity that

happened within this period. In this section, therefore, I will discuss how waiting can and

cannot be seen as a distinct period and a form of (in)activity, instead exploring how it serves

as a way of being and relating to the self in an (almost) timeless manner. In this way, I seek to query whether 'dying' is any different from other times in one's life when one lives in the wake of a mixture of progress, knowledge, and uncertainty.

In order to maintain the richness of accounts and experience, I will focus primarily on Chris, rather than use multiple examples. 'Waiting' was an element of every exchange I had with Chris, and preoccupied most of his thinking as his disease "shook up" his life and how he envisioned his future. Waiting reflected the essence of life. The elements of this account, to varying degrees, featured in other interviews and observations and together represent the complex nature of 'waiting'. At the time of writing, over a year after the completion of fieldwork, Chris was still alive and continued to look forward to "years rather than days", despite being originally introduced to me as "potentially 'end of life'". Encounters with 'waiting' leads to questions of activity, purpose, and time, and to what extent this experience represents a distinct period in people's lives.

A few months before we met, Chris was diagnosed with a late-stage cancer in his "blood and bones". His condition and the subsequent radiation and chemotherapy treatment was "so bad" that he had to quit working even though he was "only" in his mid-fifties and had never been out of work since being a teenager. Identifying himself as working class, he resented his medical condition for forcing him to "be idle". Although he was out of work, he was not inactive; his weeks were filled with routine hospital appointments and thinking about what he could do about his situation. Similar to Eriksen's (1990) point about the "art of doing nothing" when describing idleness as a social practice, 'waiting' takes on an acquired patience and ability to navigate the spaces between routine check-ups as well as the appointments themselves.

After the first round of treatment, Chris underwent stem-cell therapy; his consultant

hoped that this would extend his "healthy life by a few months" but warned him that overall

his health would continue to dwindle and no one could tell him how long the therapy would

last or how quick his "cancer would get" him. Chris no longer felt "fit and healthy" but did

not believe his current condition was "as bad as it could be", figuring he had years left to

live and that the treatments may help him "get [his] life back". Chris therefore described

himself as being in-between, neither his previous healthy, working self nor a dead man.

Being in this position, he envisioned multiple ways out including becoming "better" as well

as "getting worse". It was just a matter of "waiting this out to see what will come".

Waiting can be classified as a liminal period in that is epitomises being 'in between'

(Turner 1967), and others have described dying, or living with chronic illness, as a liminal

period (e.g. Froggatt 1997; Seale 1998; Little *et al.* 1998; Howarth 2000, Zmegac 2010;

Nicholson *et al.* 2012). The term 'liminal' has its roots in the notion of threshold and is often

used to describe the "ambiguous state of being between states of being" (Lindholm

1997:288). A problem with analytically defining waiting as liminal is that it implies an

inherent pathway complete with separation and re-aggregation as first conceptualised by

Van Gennep about rites de passage (1909). The experience and discussions of waiting,

however, did not neatly fit this pattern of movement and there was no fixed, common exit

point as the previous section about endings asserts. Therefore, whilst 'waiting' may be

described as being "in-between", which is how Chris phrased it, it is not necessarily a liminal

period in this sense as it does not represent a boundary or bounded state that ventures

onto other forms of being. Little *et al*. (1998) have described liminality as an enduring

experience for many with cancer, often lasting until death, but in doing so, they reject the

structural implications and its impact on social relationships. I argue, however, that allowing liminality to be boundless is unhelpful analytically when trying to understand how this period relates to other periods in one's life and the reasons for these similarities and differences.

One aspect of waiting which frustrated Chris was the sense of inertia that was imposed on his life. Out of work and facing mounting debts, Chris's ability to find suitable employment was further hindered by how working, even minimal hours, could jeopardise his social benefit payments. In particular, he worried that if he started working again but soon "fell ill" that the loss of benefits as well as a wage "would spell the end to us [Chris and his family]". Feeling trapped by the social systems and his body, Chris often told me that he "didn't know what to do" and frequently did not take up the activities suggested by well-meaning others that may help him regain a sense of independence and identity. Although these considerations and his clinical appointments kept him busy, the sense of inactivity and inertia are present as there are no clear paths out of 'waiting'. If it were a state or stage of life, one could presume a resolution as he transforms from one status to another. Yet, avenues out that could be explored quickly become problematic due to their potential consequences for one's health and social standing. Consequently, they present 'waiting' as an ideal position (that defies typical categorisation as a stage of life or particular role) to be in even if it is a frustrating one to experience.

The expression of inertia and the inability to find meaningful solutions are themselves part of the activity of waiting. Chris often deferred making decisions about seeking employment until the next hospital appointment, when he told me he could "ask about the prognosis" and "figure out how long [he] got". Waiting was marked by routine hospital visits, as well as

new daily tasks such as reading the newspaper and collecting his wife from work. For others I spoke to, the routine clinic appointments were a large factor of waiting and an opportunity to defy decline (and for professionals a chance to monitor and chart this decline), being reassured that they would be well enough until the next appointment. They often shared their results, reinterpreted as signs of hope, recovery, or expected decline. Although this period was experienced as a sense of inertia, without progress, there are still various activities going on which people were part of. These activities, such as clinical visits with tests, hold meaning for people and influence the way they view themselves and the experience waiting. Whilst these appointments can be interpreted as part of framing their being as one of patienthood, particularly though a focus on the body, people took them as framing an endless time.

I use the term 'routine' here to describe clinical visits as they were scheduled, anticipated, and followed a similar pattern each time. Kaufman (2005) notes how waiting can separate patients from clinical staff, particularly as staff view waiting (e.g. for results) as part of their routine whilst patients experience it as a time of uncertainty. In this study, the routine nature of clinical visits though did not relieve any anxiety attached to them. On the contrary, Chris (and others I spoke to) often felt significant changes in his body leading up the appointments, and worried that the doctor would tell him "bad news". For others, the "little niggles" often became more prominent in the days before appointments and they could feel that their body had changed since the last visit. In Chris's case, the consultant often noted how well he was doing – "against the odds" – but tempered his suggestions about holidays in the distant-future with an emphasis on "the now". Consequently, he doubted both his and the consultant's ability to know his body as what he felt did not match

her assessments. Chris often left feeling both elated and disappointed about his current status, moving forward in neither direction (towards health or death) despite the passage of time. He concluded that his consultant's responses about his prognosis equated to her not understanding his financial and employment concerns that relied on his body's ability to function. More importantly, however, was the mixture of knowing how his condition was likely to "progress and get worse" but not being able to "know when or how, or how long I've got left like this". Being told "this is your best time" but feeling "worse than ever" characterised 'waiting' for Chris in that this paradox seemed to represent for him what "the rest of [his] life would be like". Routine visits and updates from healthcare professionals, rather than alleviate the sense of waiting and uncertainty about progress, served to reinforce the sense of waiting for signs and knowledge about change as well as being neither too well nor too poorly. Although such appointments can mark a passage of time, and are used by healthcare professionals to monitor the body and any possible decline, the repetition inherent in them extends time for these subjects as this status becomes enduring.

This sense of 'waiting' had implications for how people view themselves, not only in terms of the present but also the past and potential futures. For Chris, his self-identity was entwined with working. Now faced with no employment, he lamented his past-self for "giving up hobbies to do more work" as he wished he had something "to have an interest in now", seeing it as "too late to pick up anything new". Some days he blamed his work for his condition, both in terms of the chemicals used but also in how he "pushed [himself] and ignored the body". How he was feeling in the present changed how he viewed himself in the past and he re-evaluated past decisions in light of his current experience. Similarly, he

speculated about the future and what he could "yet all do with life", wondering if he could become an author or what else he could do for his family. He did not actively make any concrete plans for these imagined future selves, but through the day-dreaming he came to reassess who he was and who he could be. Experiencing waiting therefore has implications for how one relates to him/herself and one's sense of selfhood. This finding corresponds with Bluebond-Langner's (1978) observations that dying children's sense of self shifts as they obtain more information about their condition and that this is associated with the illness process. This introspection could be said to be caused by the life-threatening prospect of dying (e.g. Tanyi and Werner 2008); yet this is too simplistic of an explanation for how the suspension of time created by the sensation of waiting allowed for this kind of reflection.

Chris ultimately felt that he had no option but to 'wait', and that through the passage of time, he would eventually find out if he would become "well enough to work" or "the bones become full of holes like sponges and finally collapse". Like many, his approach was "to take each day as it comes"; thereby neither attempting too much nor regretting if too little was done and adapting to changes in his body and mood as they came. This is different than focusing on "the now" as the consultant suggested in that it does not privilege the present over the past or the future and is different from Lawton's observation that dying patients have a "present-oriented temporal framework" often refusing to consider the future (2000:49). For people who are waiting, living like this was "no choice", and the wait was marked by the demands of others – such as the clinic appointments – and the body as much as it was about reflections about who one is and what life means. This lack of agency challenges the notion of autonomy (as presumed by policy and discussed in Section 4.1)

towards the end of life. To some extent, people have no control over how each day will progress, or what the future holds. The experience of waiting often emphasises one's inability to ultimately change "fate". The rhetoric of choice used within end-of-life care policy does not capture this complicatedness of waiting as it does not engage with the social consequences of ill-health and the changing body other than through models of decline. Whilst bodily decline may be present during 'waiting', the main experience is of not sensing any progress or movement between times or states of being.

Discussions of waiting articulate a main facet of people's lives as they experienced them. Using the language of 'waiting', however, has brought several challenges. Firstly, it implies an ephemeral period, something "that too shall pass"; however, for many waiting permeated the entire length of the research and beyond. It did not seem limited to a set time period. Instead, waiting is a state of being, with its own set of experiences and activities. Secondly, it implies that people are waiting for something in particular. This means that not only is it a transitional period but that it has a specific outcome. Although people expressed to be waiting for changes in their health in terms of "getting better" or dying, they were not necessarily actively hoping or dreading these changes; such changes were not the goal of waiting. Instead waiting took on a purpose that was broader than understanding their body and its possible decline. It was about understanding one's position in life more generally. This is where waiting breaks the mould of patienthood, even if largely structured around health and illness, in that it conjures up one's position in life and connections to others beyond those dictated by disease. Lastly, waiting implies that there are transitions from a time before and to a time after waiting, often from a state of health

to one of ill-health. As noted in the previous section, however, these transitions are not clear, and are perhaps an unhelpful way of analysing waiting.

Instead, waiting can be described more in how it is experienced and the activities involved rather than what it is not. It generates ambivalence and people do not feel they have the agency to determine the future. Instead, the agency they can have is in "living each day" making waiting no different than other times in their lives. This focus allows for an interpretation that can explore how waiting shapes relationality with respect to the self and time, and how these experiences challenge the notion of autonomy and agency over change. Overall, waiting significantly contests the linear imagery of the EOLC pathway, as in Section 3.3, and the implied control of advance care planning (see Chapter 4).

7.4: Discussion

Through the discussions of waiting and endings this chapter has brought issues and tensions from previous chapters to bear in terms of what end of life is like, the association between death and relationships, and the extent of agency one can express through these. This chapter has focused on people's experiences of how they have tried to make sense of life and death, particularly as many lived beyond the designated period of 'end of life'. Through this, it is evident that certain assumptions about dying – such as its ability to end relationships and to be managed through awareness – were not reflected in these experiences. To this extent, 'end of life' does not represent a distinct stage of life as there is continuity in relations and time.

Time is a classical issue address by anthropologists since Durkheim (2001[1912]); a key contribution of these studies is that they illustrate how time is not universally experienced. Depending on the organisation of society, the main mode of time may be defined as linear

or circular (Bloch 1977, Gell 1992), and often this mode in time runs in parallel to the way people themselves experience the passing of time, which can also be static (Geertz 1973), seem to dissolve (Musharbash 2007) and enduring (Gurvitch 1964). In relation to death and dying, Gould (2012) has noted that through knowing he was dying, linear time collapsed and time became emotional where relationships where foregrounded; this resonates with the experiences of people in this study and contradicts the pathway approach adopted by end-of-life care policy. Therefore, although time is an "inescapable dimension" of experience and social practice (Munn 1992:83), how it is experienced and conceptualised varies. This is relevant to discussions of 'end of life' as the way it is theorised by policy and experienced brings temporal issues to the fore.

The very term 'end' implies a narrative progression with a likely linear imperative with the familiar pattern of 'the beginning', 'the middle', and 'the end'. Yet even in fairy tales, one is aware that 'the end' presented, whilst closing the story told, is rarely the completion of personal stories and lives of the characters. They go on to "live happily ever after". The use of 'end' then is best seen as a way of separating segments of stories, rather than signalling the finality of all stories at once. In a similar way, 'the end' of relationships did not completely halt the potential interactions, whether they are imaginative in terms of wondering how the other person is doing to physically meeting up with them. This continuity, albeit of a different intensity and sort, is present after death as well. Consequently, 'endings' are not the same as disconnection.

Waiting challenges the linear notion of time as it held within it inertia and activity as well as reflections on the past and future. Rather than progressing from one stage to the next, waiting invited contemplation on what was experienced as an extended presence of being

neither well nor dead. Yet, the idea of stages, when applied to experiences of waiting, appears inadequate to account for how people do not move from one state of being to the next in a clearly defined manner. The transitions, if any are indeed recognisable, are so fluid that they render the notion of discrete time obsolete. Consequently, waiting cannot be fully comprehended as a liminal period as such a denotation implies clearly identifiable and marked (often ritualised) processes of entering and exiting such liminal states. Whilst the notion of feeling 'in between' was often discussed by participants, this was not the same as being 'liminal' in terms of time and status, and such a description would inadequately outline the position of persons who experience waiting

This does not mean that 'waiting' is unproblematic. It is viewed often as a state of being that is imposed upon the person due to their condition, the pace of the health system and/or their body, and the social consequences of being ill. Although many 'adapted' to this by "taking each day as it comes", there was a sense of disjuncture and being out of place with respect to anticipating and influencing the future. As outlined in Chapter 4, a key tenant to current EOLC policy is the ability to plan for the future and to make autonomous decisions about one's life and death. Waiting and the illusion of endings challenged the sense of control one had. Chris eloquently described not being able to know if he could work again or not, unable to fully comprehend the total consequence of such a decision. Similar, those trying to disengage from relationships could not do so on their will alone as others may draw them back in. If end of life is described as a time of awareness and ability to dictate one's path, the examples in this chapter question the applicability of such a view in light of how people experience their lives at this time.

Similarly, the gravity of uncertainty, which coupled this sense of lack of autonomy and agency, weighed heavily in descriptions of waiting. Waiting became a period where people had to make decisions with incomplete knowledge of what the future would be like or what they would prefer. Through the descriptions of waiting, it is clear that it creates a sense of ambivalence and this in turn influences the kinds of 'choices' people make about their futures and care. Uncertainty is viewed as a hallmark of modernity (Giddens 1991; Beck 1992; Adam and Groves 2011) and the continuance of uncertainty in this period, despite knowing that one is ultimately dying, links 'end of life' to other times during one's life. Therefore this experience and the level of uncertainty within it is not unique to 'end of life' and adds weight to the argument that people can never be fully informed in order to make these life decisions (see Randall and Dowie 2010).

Lastly, I wish to elaborate how the issues raised in this chapter reflect back on to notions of relationality and personhood. Previously, I noted how placing persons into categories – such as 'end of life' – shapes the way they are related to within the health system. In the discussions of ending relationships, the examples demonstrated how categories such as 'professional' and 'patient', as they are typically formulated, capture certain forms of relating but not others. This is particularly pertinent when concern develops between the persons and suggests the possibility of continuing interaction in a different guise. Whilst these categories may be helpful in denoting role, particularly in a professional context, they do not define persons who are part of relationships. They are too reductive to account for the ways in which people interact in a caring context and what it means to be a 'person' more generally which involves understanding the importance of maintaining meaningful relationships.

If displaying concern and care for others is part of defining one's own personhood, what is the purpose of categories that limit this kind of interaction? In part, the answer lies in the ability to have different scales of intensity of relating, some which do not require extensive expressions or connections. This is evident in how hospice nurses, for example, go about their work in order to fulfil the tasks required of them (see Chapter 5). What if the question focuses on the individual person – how do such categories define who they are? For those in this study, being defined as an 'end-of-life patient' (as in Section 3.4) does not fully resonate with who they envision themselves to be in that it does not fit with how they identify themselves. Yet, when thinking about possible futures, such categories influence the ways in which it was imagined, including foregrounding issues of health and decline whereas when not confronted with medically-defined categories people were more inclined to discuss a wider ranges of futures and ways of maintaining a meaningful role in society. Categories do not define people, but have the ability to shape the way they relate to others and themselves. Moving from the level of selfhood to personhood, categories and the relationality that unfolds from them indicate what characteristics are important for understanding the meaning of being more generally beyond the individual. This is where the importance of care and concern beyond individual relationships is apparent as it defines a purpose greater than the individual and what it means to be a 'person'.

In the account of Chris and his waiting, I also highlighted how 'waiting' is a kind of 'being'. Waiting blurs the temporal order and one is nevertheless present and connected to others and a wider context, even if suspended between them and spaces. Whilst there is not space to delve into this deeply here, I wish to discuss how this way of thinking about being allows one to connect waiting to issues of personhood and death. Here I take 'being' to represent

the experiential and embodied nature of living. In this way, a person is alive and navigates

life, through experiencing it and these experiences are largely about interactions with other

persons, objects and ideas. An important aspect of such 'being' is that care and concern are

part of it as they enable one to make connections. In this way, one's being is entwined with

the way one relates to others, bringing the argument back to relationality and personhood.

Yet if waiting is a kind of 'being', one can then ask if it is different from other times in

people's lives. I would argue that because it is not demarked by any ritualistic separation,

does not invite a neat temporal order, and entertains the need to make decisions in the face

of uncertainty it is can indeed resemble many other times in people's lives. This is

particularly pertinent if one follows the modernity argument where individuals must

continually be engaged in a reflexive project of the self (see Giddens 1991). In this way,

waiting is another aspect of this, reshaping our understanding about what it means to be.

Nevertheless, it must be remembered that many of those in this study did not die, and that

waiting may change during times of acute illness and 'active dying'; these contingencies,

however, do not negate the heavy presence 'waiting' had in their lives at this time and its

incongruence with the EOLC framework of extended dying.

7.5: Conclusion

The experiences of waiting and unfulfilled disentanglement do not readily match end-of-life

care policy's pathway approach to death and dying or notions that relationships can be

severed through events like death. Although death and ending relationships are often

presented as discrete events, they are experienced as drawn-out processes with no clear

transitions or temporal order. As in the previous chapter, the continuation of relationships

remains important for understanding personhood, even if the intensity and ways of relating

may change. This is because people understand themselves as being part of a web of care

and concern that is engaged with others rather than external to them, even if those others

are deceased.

Understanding one's own life is further expressed in the experiences of waiting. Here

ambivalence and uncertainty extend and stop the passage of linear time. Although it is

marked by routines set by outside factors, people are able to express agency in how they do

not actively engage in building their future. The apparent inactivity and "living each day as it

comes" allows for reflection on what one's life has been like and what it can still encompass.

Rather than representing a distinct period that serves as a transition from the past to the

future, 'waiting' resembles other periods of one's life and extends into them. As this defies

the linear approach represented in the pathway model of English end-of-life care, it

challenges the notion that dying, when classified as the last year of life, is any different from

being and living at other times.

Hoodie and Rolls-Royce

Summer 2012

Fieldwork ended more than a month ago and I've gotten into the mode of 'not being in touch'. In the back of my head I wonder how they are doing. I wasn't supposed to be in this situation. Good-byes would have been more permanent. Instead I had offers to go around for tea when I was bored with writing, them inviting their 'new friend' to visit. I can't quite get myself to go. Although I often wonder how everyone is and I am curious. Funny how a few months ago I felt like a vulture waiting for people to die and now here I am wondering how to cope that they are still alive.

My reluctance is so grand that I panicked the other day walking to the post box.

Image 12: The bridge that cannot separate fieldwork-relations from personal daily life.

Un-showered and in my working-from-home clothes I planned to nip over the bridge. But as I came over the hill I spotted their car – of course I would, it was lunchtime on a Tuesday and they eat there every week. To get to the post box I'd have to pass their car and the restaurant. Up came my hoodie as I crossed the road, hoping they'd not

spot me. If I were spotted, or if I spotted them, I'd feel obligated to go over and say hi, or feel bad for not doing so. And I was bound to hear a word or two about my unkempt appearance.

In their reply to my thank you note they told me they bought a plant named after me. A sweet gesture but I will now forever be in their garden (unless they kill 'me' off…). And they are in my thoughts. Our lives have become oddly entangled through 'research' and in way, what constitutes each of us has a sliver of those afternoon teas.

I'll send another card someday. Just not today.

Part 4: Discussion and Concluding Remarks

Chapter 8: Discussion

8.1: Introduction

In contrast to the linear portrayal of choice in end-of-life care put forward in the National

End-of-Life Care Strategy (DH 2008) and represented as a pathway discussed in Chapter 3,

the previous descriptions and discussions have entangled 'choice' and 'dying persons' in

webs of relations. Each chapter has shown another possibility of how 'choice' and/or 'end of

life' may be configured, negotiated or experienced. In Chapter 4, I outlined how the forms

used to elicit patient choice and people's past experience influences the choices declared

whereas in Chapter 5 I outline how choice is done as 'work' within healthcare settings. In

contrast, Part 3 illustrates how people navigate daily living, rather than choice or end of life

per se, through the relationships they have with others and themselves. In effect, the

emphasis on the individual and their discrete choices as depicted through the discourses

and practices in Part 2 are not mirrored in the experiences discussed in Part 3 and through

this I have argued for a wider view of personhood beyond the notion of individual. The

purpose of this chapter is to link together the various threads, play them against one

another, and push the boundaries of what has been stated so far. In doing so, I take a step

back and critically evaluate the study, what implications the analysis may have, and how

various aspects of the research could be explored further.

In the first section, I address the main thesis of this work – the centrality of relations and the ability of relationality to explain the complexities of choice and end-of-life care. In doing so, I highlight what such an approach allows and excludes, including how a focus on relationships shapes the concept of personhood. The following sections outline the implications of understanding 'choice' and 'dying' based on a relational approach and in light of the previous discussions. Subsequently, I query the importance of putting weight on both, not only from an analytical standpoint but also as an importance for healthcare policy and practice. Since neither is as straightforward as the policy rhetoric implores, I question what their value is. By focusing on relations, the singularity of individuality that is the emphasis of 'choice' in English end-of-life care is challenged.

Consequently, I consider the possible applied implications of this analysis. Whilst the explicit aim of this study is not to reform care or the delivery of health services, the questions I raise are "good to think with", to borrow Levi-Strauss' phrase (1963:89), in terms of how end-of-life care is set-up, delivered, and experienced. As part of this, I turn the mirror on the purpose of research. In particular, I engage with the notion of impact, which is currently a key marker of value in health services research. I explore the kinds of impact, if any, this kind of study can have if not directly applicable to service evaluation and reform. Lastly, the final section outlines the main contributions and limitations of the current project as well as highlighting the questions this research has raised that could be examined further.

By exploring choice in relation to English end-of-life care, I have demonstrated that neither is as bounded or clearly identifiable as they first appear when reading health policy. The experience of doing choice and care, both full of interaction and relationships to others,

allows one to consider the nature of experiencing 'end of life' and personhood. Through a discussion of the main themes, this chapter suggests that looking at choice in relation to English end-of-life care illuminates other aspects of life, being and death.

8.2: Relationality

Throughout this dissertation, I have taken a relational approach to the topic as a way of examining how end-of-life care and the emphasis on choice shapes healthcare provision as well as how people experience being in this phase of life. Besides relations being at the core of anthropological interpretations (see Section 1.2), I wished to foreground these connections as it is through relating to the people in this study that I came to know them. Similarly, this relational knowledge is in the spirit of English end-of-life care policy that seeks to be patient-centred and orient care around them. This focus on the individual, whilst also suggesting the web of connections they could be part of, lead me to thinking about the link between individuals, personhood, and wider systems of care. I was therefore curious how end-of-life care shaped the way people were related to, in the very interactions of care, and the relationships they were part of. This section discusses what this relational approach has been able to demonstrate, and how relationality is implied when death is appealed to.

   End-of-life care policy emphasises the role and position of the individual (dying) patient; it is their choice around which care is to be organised and their death that is to be managed. The discourse of individuality and choice foregrounds notions of autonomy and an isolated being who is uninfluenced by outside factors. Yet, even within policy rhetoric and the imagery of the EOLC pathway, it is evident that these patients are not alone per se and untouched by the world around them. Indeed, their declining bodies necessitate the foregrounding of death and the need for health services and professionals to be responsive

to changes in the patient's condition. Preferences place the 'individual dying patient' within a larger system and set of relationships. However, whilst the patient and their care may be relational, their choice as rhetorically referred to in policy, is to be individual. This may appear incoherent, particularly after the last four chapters have demonstrated the way choices are influenced by factors outside of the individual and the moment in which choice is articulated. The view that choice can be individual relates to a long philosophical history of autonomy in 'Western' cultures (Brender and Krasnoff 2004), where not only the person can be viewed as individual but their thinking can be equally unattached in that it is unaffected (see Gordon and Niznik 1998).

Rather than focus on the notion of 'individual', I have emphasised the nature and connections of the person. The latter term immediately connotes relationality (Strathern 2005), and it is this concept of the dying patient that is at the heart of EOLC policy as it seeks to be patient-centred around the individual (although through the framework it constructs such persons as declining bodies and reflective subjects). Indeed, the move towards personalised care, rather than individualised care, may hint towards this approach (see Owens 2012). Whereas the concept of the individual implies autonomous abilities, the notion of person allows for a more dispersed approach and to account for the context in which they live. A person-centred approach to healthcare should therefore not only be concerned with individual preferences (whilst acknowledging that these are influenced by various factors and are not strictly autonomous in the purest sense of the word) but also how persons are part of a wider social structure which will be affected by changes in them and their care.

I discussed this in Chapter 6 by illustrating how important relationships are to people who may be considered 'end of life'. In particular, maintaining familial relationships was significant to the people in this study as a way of sustaining their own sense of self and identity. It can be argued that it is through relationships with others that one knows themselves (Hockey and James 2003), and indeed, through relationships between ideas that one concept becomes distinct from others (Rapport 1999). In this way, relating leads to dividuation as each person is a part of a unique constellation of relationships. In the context of this study, it is about seeing how these relationships affect the way a person is cared for, and how they experience their life as they live it towards 'the end'.

If relationality is important for understanding personhood in life, the question remains to what extent relationality allows for a discussion of death. In the last two chapters I discussed how death, to varying extents, could present a severance of connections. Classically this has been thought about as death serving to reorganise the social order (Bloch and Parry 1982), and there has been an increasing interest in how people continue bonds after death (Howarth 2000; Valentine 2008). The ontological turn within anthropology has questioned whether relations are always central to understanding social life, and to turn one's attention to the ways in which relations may be severed, purposefully curtailed, and/or maintained but at different intensities (Candea 2010; Palecek and Risjord 2013). It would be inaccurate to state here that people are always related to others to the same extent, and the discussions in the previous two chapters demonstrate how people manage their relationships with others in a way that indicates more nuances that the terminology of connection/relation/detachment allows for. What I explore here, however, is to what extent personhood, based on a relational approach, remains when death is present.

I would argue that relationality continues, albeit in different forms. For example, Matthew continues to think about his mother even after her death and continues to interact with objects from her life, such as her house, and these serve to represent her in the present even if she is no longer herself physically present (see Section 7.2.1). By focusing on personhood (the status of being a person) rather than selfhood (the state of having a distinct identity), how the 'person' through relations can remain, even if their identity, body, and role has changed can be examined. Therefore, death cannot claim to detach persons from the physical world as is often presumed because they continue to exist through the relationships that were part of them when they were alive.

Proponents of the theory of social death, however, would claim that a person does die through the severance of relationships (e.g. Middleton 1982). I do agree that how people are interacted with can change as a result of the way the body changes (see Sudnow 1967 and Chapter 3), but that such changes do not necessarily equate to the 'person' being considered dead. This is because personhood, in this analysis, is more than the body and the mind, but the way a being is positioned within a wider social network. Such a view of personhood is more common of studies of other cultures (e.g. Lienhart 1985; Smith 2012), but through the analysis of being in within the family, I contend that it can apply to English notions of personhood as well. So long as they are still viewed as impinging, being part of, or interacting with others – through whatever means possible – they are still considered to be a person. Relationality therefore is integral to personhood, even in the context of death and dying.

Overall, my focus on relationality has brought several key issues to the fore. Firstly, it has foregrounded that changes in policy affect the ways in which people relate to others,

themselves, objects and abstract concepts. In particular, changes in policy shape the way patients are categorised which has implications for the way health professionals approach their care (see Chapter 3). This highlights the social nature of healthcare delivery. The discussions of how choice is done illustrate that although discourse implies that choice is autonomous, it is embedded within a larger context that extends beyond personal expression. What is considered 'choice' is constructed by policy, and what is articulated as preferences is influenced by people's past experiences, the situation in which such statements are made, and even the material objects onto which wishes are to be documented. Relating therefore is not just between people but also between times, experiences, and objects. By attending to how choice relates to end-of-life care, it is clear that it shapes the way 'care' is envisioned and provided as an element of work and part of an obligation to patients.

In Part 3, the focus on relationality was less about the clinical and practical practices of identifying death and articulating choice. Instead, through discussions of relationships I emphasised the nature of personhood and experience as a way to illustrate the very persons that are at the heart of end-of-life care policy. Other authors have suggested that personhood is located in the body and that death threatens personhood because of the disintegration of the body (e.g. Lawton 2000). Whilst I do not disagree that embodiment plays a role in how one understands the self, for many of those in this study, it was relationships to others and how their ability to continuously interact with them that was important to them. The body has a role in this, but was not positioned as the main factor that determined this. My interpretation has focused less on the body, choice and managing the future, which are the aims of policy, and more about being connected to oneself and

others, particularly though displaying care and concern. Through this, I wish to stress that it is these connections, rather than choice per se, that is important to people. This does not mean, however, that relationships are unproblematic as the discussion of endings in Section 7.3 indicated. Not all relationships can be maintained at the same level throughout time, and it is not only about maintaining connections, but also navigating those relations, which is important. In this, the multiple agents involved in any one relation become clear, highlighting that relationality is not unidirectional, particularly when affect is considered. Ultimately, a focus on relationships demonstrates the complex way in which choice and care are known and through these broader statements about what it means to be a person can be illuminated.

  While categories, like terminal, can affect the way professionals seek to interact with patients, people themselves are able to modify, to a certain extent, these interactions. One way of doing this is asserting their parent role within families. This continues their sense of self and social position in a way that was congruent with past experiences. I point this out because English end-of-life care policy identifies people as subjects through their choices and through their declining bodies, both thought to be located in the individual, whereas people identify themselves through their experiences of daily life and interactions with others. This often extends beyond the formal period that is designated as 'end of life', meaning there is a disjoint between policy images and what people experience.

  This approach to analysis has been helpful in articulating the social embeddedness of persons, and thereby countering the rhetoric of the individual. However, by emphasising the complexity involved, such an interpretation struggles to neatly limit the context to which it alludes to. In order to convey certain messages here, I have had to select which

connections I make and which wider contexts I include; however, for each choice there are

numerous others which have not been mentioned. Therefore even within a study grounded

on relationality there are discontinuities present. I have chosen to focus on how concepts

and practices shape the way, for instance, people relate to one another. This does not mean

that the other connections are unimportant, such as the meaning of 'home', and many

could be further explored. I make this point to demonstrate how a focus on relationality has

(un)internationally created its own disconnections.

The method of ethnography has aided the relational approach adopted here. Through this

I have been able to place the discourses surrounding English EOLC into their wider socio-

cultural context, both in terms of a history of palliative care (see Chapter 3) and political

history of increasing neoliberal choice (see Chapter 4). Moreover, this research directly

looks at the relationship between policy and health care practice. For example, the way

choice is turned into work is an indication of how policy objectives are being operationalized

within the National Health Service. More importantly, the focus on relationality has allowed

me to demonstrate the disconnect between what policy envisions end-of-life care to be like

and how people experience it. It is through the emphasis on how relations are integral to

personhood that one is able to appreciate the embedded nature of life, death and dying in

England today.

8.3: Choice

Choice is a key concept within EOLC care, yet how it is done and what constitutes choice is a

complex process. The choice rhetoric in policy implies that patients can be individual,

rational subjects who can imagine their future decline and death. Documents have been

devised to enable patients to express their preferences about their EOLC and these are to

be routinely used within clinical practice, although there was little evidence of systematic use at the time of this study. Such tools and the encounters in which they are used influence the way 'individual choice' is articulated and understood. Moreover, the preferences that people expressed often illustrated the relationships they were part of and the concern they had for others. This section revisits the notion of choice, the underlying values implied in the policy discourse, and how a relational approach to choice reflects the nature of 'choice' in the context of end-of-life care.

In Chapter 4 I outlined some of the main critiques of 'choice' as a policy concept within neoliberal settings. These critiques describe it as unrealistically idealistic about the individual and their ability to make rational decisions that maximise value. They rely on the notion of an autonomous individual expressing their agency. Yet, the descriptions of 'choice' in the proceeding chapters illustrate the varied ways in which 'choice' is constructed and negotiated, and that what is divulged as 'individual choice' is influenced by many factors that may appear to undermine the notion of individual autonomy that the word 'choice' implies. Here I will illustrate how the different examples undermine the notion of choice as being the result of a rational, maximising, individual decision.

The first element of the ideal notion of choice to be challenged by the data presented here is that 'choice' is ultimately rational. In philosophical terms, rationality does not hinge on empiricism but logic, and can therefore bracket out the ability for others and objects to have affective agency and thereby influence one's ability to make decisions and take actions. Additionally, it privileges information, evidence, and 'facts' through which options can be weighed up. Making decisions rationally is colloquially referred to as making them "with your head rather than your heart" to emphasise a thought-process devoid of

emotionality. The descriptions presented in Chapters 4 & 6 illustrate, however, that there are many things, both objects and people, which have the ability to influence choice in ways that may not be 'rational'. For instance, people drew on their emotional connections to past experiences and how they imagined the future to determine where they may like to die, rather than consider the kinds of clinical treatment that may or may not be available to them in different settings. They often have little information about what their own death will be like, but nonetheless expressed preferences about where it should occur. Moreover, the focus on place was often triggered by the advance care planning tools people had in front of them (or had previously seen), and was not necessarily a key consideration without this prompt. Therefore 'choice' was influenced by affective elements, as well as rational considerations, and the context in which preferences were being stated. This finding is similar to studies demonstrating how people make seemingly 'irrational' choices (Airely 2008) and indicates that a model of choice based on rationality does not readily apply to these kinds of decisions.

  The second element of 'choice' is that ultimately decision-making should maximise one's position, usually in economic standards, but also their relative health (e.g. Edwards and Elwyn 2001). When it comes to death and dying, it is unclear which one of these elements people should theoretically be striving to maximise, but within EOLC policy, the quality of the dying experience is stressed and therefore this discussion will focus on that experience and managing 'decline' to enable a 'good death'. If we take Barbara's example of continuing to care for her grand-daughter even though this exacerbated her poor health, her behaviour would not be viewed as maximising the quality of her dying experience as it resulted in frequent, and uncomfortable, hospital admissions. However, maintaining relationships with

others, particularly family members, is important for people (see Chapter 6). Therefore, whilst caring for her kin decreased her relative health status, it served another purpose in maintaining connections. Rather than maximise her own health, Barbara privileged her relationships with others. Similarly, other informants described how they often took action that put their children's well-being before their own. Oscar and Rosalind's decisions to be cared for in certain settings were not necessarily so they could have 'good deaths' but because being at home or moving closer to family helped maintain the kind of caring relationships they wanted. In this context, if 'choice' is to be seen to be maximising, it is not necessarily to maximise the likelihood of a 'good death' but rather to maximise the ability to maintain connected to select others, such as certain family members. This social orientation of the choosing person contrasts with typical depictions of humans as *homo economicus*, seeking to maximise their economic ability (e.g. Thaler and Sunstein 2008; see Read 2009 and Gill 2012 for critiques). I would argue that such an emphasis on relationships and the social nature of decision-making is not limited to end of life, however, as many of the discussions, particularly of putting children first, resonated for people across their lifespan.

The last characteristic attributed to choice is that it is made by an individual. The concept of 'the individual' is problematic as it stresses isolation in terms of independence and autonomy (see Chapter 1; Morris 1994:148). Here I address the related concept of autonomy, which is often thought of as individual autonomy. Autonomy refers to the ability to self-govern and one's freedom of action; in essence, the individual has agency over themselves and their lives. The ability to act as freely as this concept implies has been challenged already in terms of how specific preferences can be influenced by thoughts about others, considerations about what is the norm and how one should behave in certain

scenarios, and the material objects used to elicit choice. Reflecting back on the exchange between Oscar and the hospice nurse (Section 5.4), his preference for dying at home was necessitated by the hospice paperwork and negotiated in his interaction with her. This process of negotiation and what I shall term here loosely as 'outside influence' undermine the notion that Oscar was fully autonomous in this instance and that his preference to die at home represented an autonomous choice. Therefore the process through which 'choice' is articulated in advance care planning is not as autonomous as the policy rhetoric portrays it.

Additionally, when later talking about where he would want to be cared for, both Oscar and his wife Pamela, expressed how the decision for him to be cared for at home was a shared decision and how it was best for them both. This means that people take action based on how it will affect those around them and the relationships they have with others. As well as shaping decisions, these relationships are important for how people know themselves. Yet, the only relational aspect of individual personal autonomy is the relation to the self. The situations in which choice became known demonstrate that agency is not an individual property but dispersed in the context of end-of-life care choice. Instead, the concept of relational autonomy may best represent how 'choice' is done within the context of end-of-life care as people are embedded in social relationships and these relationships influence the way decisions are made (e.g. Mackenzie and Stoljar 2000). Being aware of the relational nature of personhood and choice would relocate 'choice' from the individual to their web of connections.

Salecl (2010) claims that people make decisions based on the links they wish to have with others and how they think others will view them. This view is supported by the observations, particularly when reflecting on how forms are completed in clinical settings.

Yet, I suggest that there is more to how choice is influenced by relations and that people also relate to ideas and objects, such as the physicality of the forms, and this too has an impact in how choice is formulated. This is more than stating that decision-making is about the relationship between structure and individual agency (c.f. Smith 2009). It is not necessarily a duel between the individual wishing one thing and being encouraged to state another based on policy desires. Instead, I contest that it is in the murky interplay between persons, their wider networks, the context in which they are making decisions, and the frameworks in which choice is acknowledged that 'an individual's end-of-life care choices' are created. Viewing choice in this way allows for more flexibility in how it is to be followed within the end-of-life care model as it is no longer the sole representation of a person but an indication of the wider social context in which they live in. If, however, English end-of-life care choice were to be understood in this way it would undermine the rhetorical ability of policy to mobilise change within the health service, which is currently geared towards patient-choice.

The current emphasis on 'choice' in end-of-life care policy is employed because it is presumed that patient-choice will lead to a better dying experience and therefore a 'good death'. In Chapter 5, I demonstrate how 'choice' is being mobilised to demonstrate 'care', rather than oppose it. Yet, for some readers this does not necessarily lead to what is considered a 'good death' or even 'good care'. For nurses, institutional requirements to know a patient's choice but not record or act on the wider context, which influences such statements, may be viewed as neglecting to take a holistic view. For Mable, a focus on 'choice' and home death meant weeks of uplifted hopes about a discharge only to die in a care home. Singular as these examples may appear, similar accounts were readily provided

in interviews. I wish to stress that it is not the fault of the individual staff, carers, or idiosyncratic cases but the system-wide approach that emphasises a certain aspect of care – patient choice – over other elements of interaction and dying. The way choice has been operationalized within healthcare practice does not mean it will automatically lead to the goal of end-of-life care policy that is 'good care' and a 'good death'.

Part of policy's emphasis on choice is that people can choose where they want to be cared for and die. This choice of place is often taken as a discrete object (see Chapters 4 & 5) and it is presumed that one's preference for place represents what they view as a 'good death'. By using terms like choice and preference, policy positions this decision as one of want, rather than need or compromise. Yet, the ways in which this 'choice' was described often indicated that the place chosen represented more than a personal desire to be in a specific location. It indicated past experiences of death and care, where other locations may have been alienating or lacking the provision expected. One's chosen place also represented the relationships one was part of – for example a desire to be near family or a concern for the burden a particular setting would create. Rather than being choice that represented an individual's own desires, place reflected the wider network of relationships and care a person was part of.

Instead a stance, which acknowledges the relational aspect of persons and dying, could be embodied in end-of-life care that seeks to be person-centred; however, the current emphasis on individual choice would no longer be appropriate. Hallowell (2009) discusses how informed consent, based on the notion of the individual, is inadequate for understanding how and why people take part in genetic testing within a family context, and similarly here, a narrow focus on the individual cannot account for how people 'makes

choices' when those choices impact others within the family. It would be more appropriate

to frame EOLC in a model of care, moving away from the language of 'needs' and

'preferences' to how actions allow for the expression and receiving of care and concern.

This kind of approach could still enable the processes of thinking about future care plans,

but in a way that does not set up a false illusion about the ability to make a reality of

individual choice. Moreover, it would more accurately represent the negotiated and diffuse

process of making decisions about the future in the context of healthcare and dying.

  End-of-life care choice, although rhetorically emphasising the individual, is more about the

relational aspects of living, dying, and being cared for and caring for others. Taking a

relational view about choice acknowledges the network that people are part of it and how

stated preferences can be influenced and informed by 'outside' factors. Recognising this

does not necessarily remove the agency of stated preferences within the practice of EOLC

but allows for a more nuanced understanding about how these choices reflect one's

position and the care they receive and provide.

8.4: Revisiting Death

Up until now I have reframed how choice and care can be thought of in the context of end-

of-life care. Now I turn my attention to the underlying impetus of such policy, which is to

focus on death and dying. As I discovered throughout this research, the concept of 'end of

life' and the current timeframe applied to it does not capture all deaths or the ability to

foresee when death will occur. Nevertheless, it remains a useful rhetoric for mobilising

redevelopment in healthcare services and public support for policy, as policy-makers

frequently stated "we all die sometime". Here I discuss what a focus on death allows, both

politically and in terms of research, and how death and dying are being reshaped through these discussions.

   In the first instance, by focusing on death, the policy becomes immediately linked to all citizens, regardless of age, as every person will die and will know others who have died. However, most healthcare policy focuses on a medical condition, and death is not immediately considered a 'medical condition' or abnormality, other than it represents no longer being (healthy and) alive. In Chapter 3, I discussed how death has become medicalised, and that the revivalist discourse surrounding death, which includes dying people being aware of their mortality, is now part of how healthcare professionals are to approach death. In particular, the view that a good death can be achieved through advance care planning revisits older models of preparing for death (see Aries 1981). Current policy has incorporated a wider view of death beyond the physical cessation of bodily functions. By addressing issues of social death and striving for a good death, managing the dying process and its wider context is now part of medical policy. In this way, what death is and how it is to be approached has changed. These changes will shape the way death is approached in the future, particularly from a medical standpoint.

   However, the discussions in Part 3 highlight that end of life is not experienced in the way EOLC policy posits, where death is foreseeable and dying is a process of linear decline. Firstly, dying is not necessarily a linear process. This applies not only in how physical decline may be interspersed with recovery, but more importantly in how waiting marks most people's experience of this time. Moreover, many people were faced with knowing they were unwell and will die, but unsure of when and how this would happen and this uncertainty was not managed within future care planning as policy suggests it can be.

Policy's focus on death encourages people to actively engage with this part of their lives, but the way many lived on a day-to-day basis emphasised how similar this period was to other times in their lives, both in how the future was relatively unknown despite a certainty that they would die and in how they maintained relationships with those close to them. In this way, end of life, in spite of being seen as 'dying', was not necessarily different to other times in people's lives. Consequently, the everydayness of this period undermines the special attention policy places on death and dying.

The category of 'end of life' has been created to encourage doctors to identify dying and talk about death with their patients. It is to encompass the last 12 months of life, but many of the people that could be placed in this category either live beyond this time frame or die in a shorter period of time. During this study, there were no clear transitions for when someone entered this phase. For those that died, the process of dying was gradual with only marked changes in the last few days of life. Yet, even then people including clinicians, thought that they may not die. Therefore, whilst in principle the category is useful for discussing and planning death, in itself it cannot capture dying. Moreover, from the experience of people in this category, rather than claiming 'end of life' as a distinct period, it blurs into the general passage of time and ageing. By using a year as a marker, which is an arbitrary cut off even with reference to physical decline, 'end of life' becomes an extended period that further blurs the boundary between life and death. Therefore, whilst it may be useful for policy, it is not discrete enough to be analytically astute on its own merits.

A major contribution to dying studies from the social sciences has been the identification of a social death which is distinct from, and precedes, when the physical body dies (see Sudnow 1967; Lawton 2000). Others have demonstrated how various conditions and care

practices may shift the way in which persons are related to and in effect exclude them from society (e.g. Townsend 1997 regarding 'the elderly; Nettleton 2006 regarding medically unexplained symptoms). Such studies suggest that in later life, or as bodies decline, people are passive recipients in social interactions. English end-of-life care policy seeks to avoid this by being patient-centred and encouraging the expression of autonomy as the representation of personhood. In this dissertation, I have illustrated how beyond expressing choice, people are active agents in interactions and are able to maintain key relationships that are integral to their personhood. The people involved in this study did not suffer from a social death, as theorised, and this was not the result of being involved in advance care planning. Moreover, although the way they were related to changed after death, many of their kin continued to engage with them as persons. This suggests that the notion of social death and the way relationships are involved in determining personhood and life should be revisited from a theoretical stand-point, at least in the context of the extended period of dying which 'end of life' is.

  Kellehear (2008) considers dying to be a social relationship in itself as how it is defined and identified reflects the wider context in which people are embedded. Similar to the version of personhood that I employed earlier that emphasises the inter-subjective nature and connections that are bound in what it means to be 'a person', Kellehear's argument is that a person (and their body to some extent) cannot be considered dying or dead unless those around them see, and agree, that it is so. Whilst we share similar interests, rather than follow this line of thought, I illustrated how these relations are shaped, practiced, and discussed – the focus has been on the relationships rather than dying per se. Dying can therefore be as much a social process as a biological one, but rather than asserting that the

process is a relationship in itself, I seek to discuss how it is informed by and affects relationality.

By representing other aspects of their life, experiences that occur in the period designated as 'end of life' suggest that it is not a significantly different period of time other than being declared so by healthcare policy. This category is useful for mobilising health services but it does not reflect people's daily experiences. By focusing on particular notions of death, English end-of-life care policy is reshaping the way death and dying are socially understood. This is currently influenced by the revivalist discourse that privileges awareness of dying and the dying person actively being involved in the planning of their death. Policy posits that this will negate a social death; however, this research indicates that a relational approach to personhood where dying persons are considered active agents is more explanatory in understanding how people maintain their roles and social positions towards the end of life.

8.5: Implications

In this section I wish to outline some of the implications this study has for end-of-life care policy and practice as well as the way in which contemporary (health) research is framed. What joins these three areas together is an emphasis on impact and improving quality. As a discipline, anthropology has often sat uneasily in relation to direct application of its findings (Wade 1995); however this does not mean that the insights such studies generate cannot inform practice, even if unintended, as the process of sociolization indicates. Here I forge connections to the above analyses and current policy and practice positions.

End-of-life care policy makes some key assumptions about people, their backgrounds, and their deaths that have implications about who is affect by policy, or phrased another way, who policy is for. The focus on choice, individuals, and care within the home, is typically

culturally aligned with educated, white-British, middle-class persons who can afford to live

at home and have family members who are physically and financially able to support them

at home. It also presumes that one's symptoms are visible enough to foresee death but not

'too messy' to be accommodated within private, personal spaces. However, as evident

within the interviews and observations I conducted, not everyone comes from such

backgrounds, and even if they do, they may not have the ability or circumstances that

correspond to the underlying assumptions within policy. I dissect the implications this has

further in relation to choice and death below; however, it is important to note that current

EOLC policy, in its formulations and how it is being practiced, creates an implicit inequality

as well as an attempt to normalise a 'privileged' way of dying.

  Secondly, I address the current emphasis within English EOLC on individual choice. As I

have outlined above, neither the 'individual' nor 'choice' are as isolated as implied in policy

rhetoric. Nonetheless, I accept that this emphasis has provided the impetus needed within

the National Health Service to create service change that provides more aware and

responsive EOLC to patients, including discussing the progress of dying with patients and

allowing them to express their preferences. In this way, these changes resemble the change

to maternity services that occurred in the early 1990s. However, from my observations, the

concern is that positioning choice as an ideal and goal to work towards, which requires

patients to be openly reflective and forthcoming with how they imagine their death, poses

the risk of negatively labelling patients or their deaths if this does not occur. It is not

uncommon in healthcare for 'uncooperative' patients to be viewed as deviant (e.g. Lorber

1975;), and those that do not engage with advance care planning have been considered to

(negatively) be 'in denial' (Borgstrom *et al.* 2013). Similarly, if advance care planning and

patient choice are requirements for a 'good death' as set out by EOLC policy, deaths that do

not include this are through implication 'bad', due to the ability of policy to create new

norms.[66] I contend that neither of these consequences are intended by policy and yet the

emphasis on choice creates such possibilities.

Additionally, as demonstrated in Chapter 5 on the practice of doing advance care planning

in clinical settings, 'choice' can become treated as an organisationally-driven task rather

than an on-going, patient-driven process. This is often a pragmatic approach adopted by

institutions and staff as a way of operationalizing a value system; however, it runs the risk

that the very values that advance care planning seeks to embody are obscured in the

process of documenting. For example, patient autonomy is reduced to describing a single

preference. Similarly, a strict focus on place, which is encouraged by policy and the use of

tools like the Preferred Priorities of Care document (PPC), may side-line other aspects of

living with conditions or dying and death that people wish to express and manage. It is this

negotiation between professionals and patients, which Mol (2008) pursues, that can be lost

when 'choice' becomes a task. In this way, 'choice' may no longer be about the patient and

this serves only to undermine the purpose of changing policy and practice.

Besides the audit-culture nature of much of healthcare, one of the reasons 'choice' is

treated as a task rather than an engagement with patients is that the document is itself not

conceived as a relation but as an object. Yet, the implementation of advance care planning,

and many other aspects of end-of-life care, relies on relations and relationality between

various persons. The underlying dissatisfaction with the process, as described in Chapter 5,

is in part caused by the marginalisation of relating to patients that focusing on paperwork

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[66] Similar observations have been made about EOLC conversations – see for example Barclay *et al.* (2011).

may create. Similar concerns have been raised within the UK more generally in relation to the care of hospital patients and the use of the Liverpool Care Pathway (LCP). Whilst many of the healthcare professionals I spoke to felt comfortable filling out EOLC tools like the Preferred Priorities of Care (PPC) document, they did not express the same confidence about relating to patients and having the time to listen to their concerns. In effect, healthcare professionals felt they could not care for patients the way they wanted to, and in some instances this resulted in them choosing not to use EOLC tools. Consequently, within policy and practice it needs to be acknowledged that 'best practice' tools are useful not only in and of themselves, but in the relationship and space for caring they can allow for if staff are given the time to engage with patients and that in some circumstances their use may not benefit the patient, professional, or their caring relationship and that not using them is not equivalent to failure. As the LCP review has highlighted, professionals need to know not only how to use such tools, but when to use them (or not) and how to relate to patients as they do so.

English EOLC policy seeks to manage death, in particular through identifying dying and placing patients on 'the pathway'. This view that death and dying can be managed, and that this management can be facilitated through choice, as outlined in Chapters 3 & 4, can function as a screen that blocks the messiness of dying that others have highlighted (e.g. Lawton 2000). In such clear imagery as the EOLC pathways, the complicated nature of dying and the way it can unpredictably unfold is not visible. Similarly, the experience of waiting that many described and the need to make decisions with incomplete knowledge is not incorporated into current policy and its understanding of what being at the end of life is like. In a system that is predicated on knowledge and control, such experiences may never fit

and it may not be appropriate to try to integrate them. To an extent, therefore, EOLC policy represents an illusion about the ability to foresee and control the future and the body. This does not mean that it is ineffective; rather I wish to note that this uncertainty could be more openly acknowledged and embraced within EOLC models.

My next point refers to the role of the family in EOLC policy and practice. It was openly acknowledged in observations and interviews that the current policy does not consider the role or the needs of the family much, although doing so could improve their experiences of the death and bereavement (Payne and Grande 2013). Instead of focusing on their role and experience, my research highlights how policy does not incorporate the importance of personal relations, such as familial relations, for the person in its conception of what makes a good death beyond their presence. Since maintaining and expressing connections is important for personhood, and EOLC policy wishes to honour the person, more could be done to understand how relationships inform a 'good death'. Exploring these connections in healthcare practice, however, could make more 'work' for the professionals and this leads me on to my last point.

Throughout the research, I often wondered if death was really the domain of the health service. Others have argued that it has become medicalised through a process that first sought to delay dying, and now to understanding dying (Seymour 1999). Many of these critiques, such as Illich's (1976), highlight how death has not always been regulated by medical professionals and some question if there is room for other sources of oversight (e.g. Rosenberg 2011). The modern hospice movement was founded in part to respond to the medicalisation of death, and yet, during the last few decades hospices have become incorporated into the healthcare system (Bradshaw 1996). The increasing scope of what is

involved in the care of the dying – from treating physical symptoms to the incorporation of

spiritual care – means that the kind of care medical professionals and the health service are

expected to provide patients is increasing. In some instances, this extends beyond the

traditional format of diagnosis and treatment of physical ailments as depicted in the hospice

model. The reason dying is a concern for healthcare policy, beyond the physical

management of bodies, is that the NHS is considered a 'cradle to grave' service (Rivett 1998)

and tasked at improving the quality of people's health and medical experiences, which dying

is considered to be part of.

So if policy's role is to improve the care of the dying, what is the role of research in EOLC,

particularly in this case where findings do not directly apply to healthcare practices? Rather

than make an argument that research should align with policy to improve care, I outline

how research provides impact besides being directly applied in policy or healthcare practice.

As noted earlier, many of the long-term participants outlived the length of the fieldwork,

even though when relevant clinicians were asked, they could have potentially been in their

last year of life. Not only did they outlive the length of the study, for many they noted

improvements in their health during the course of the research, which they attributed to

our visits. When I queried this, Christina, for example, said "it's because someone takes the

time to actually know how I'm doing" and Oscar noted that the visits "give me something to

look forward". Other end-of-life care researchers have commented that participation in

research can have therapeutic benefit (Kendall *et al.* 2007; Buckle *et al*. 2010; Gysels *et al.*

2012). These are often intangible aspects of research and are a product of the relationships

engendered through the encounters; these can be personally valuable to researchers as

well as participants (Glowczewski *et al.* 2013). The impact therefore of this study can be

seen on the scale of the person and the relationality that participation involved. Rather than thinking of the grand differences research can make on a societal level, this illustrates the direct impact it can generate for those taking part and that this kind of impact, whilst limited to those involved, is nonetheless valid in terms of thinking about how research can shape and improve people's experiences.

This research can therefore provide impact in several different ways. Part of this is the impact it has already had for those that participated, based on the personal relationships forged through the ethnographic process. In addition, the insights gained from this study can have implications for how end-of-life care policy is designed in the future and how policy is operationalized into practice. For example, if current practices continue, the meaning of 'choice' may be lost as the process is focused around completing tasks. With an increasing focus on documentation, healthcare professionals may not have the space, time, or energy to engage with patients on a relational level, thereby treating them as persons, which may allow them to acknowledge experiences of waiting and the importance of familial relationships, which are currently side-lined in favour of demonstrating 'best practice'.   Not only does EOLC policy need to widen its concept of who a dying patient is and their want (or not) to be part of managing their dying, there needs to be more flexibility in how end of life is approached, foregrounding a relational rather than individual approach to life and care.

8.6: Unbinding the Study

Earlier I addressed the conceptual and practical implications arising from the analyses. The focus on relationality and personhood demonstrates the differences between policy discourse and the experiences of practicing and experiencing 'end of life'. In this section I

describe the key contributions and limitations of the study. Additionally, I suggest how to

improve upon this research and/or carry it forward as there have been several theoretical

areas that have been sparked by the current analysis that have not had space to be explored

here.

Firstly, the study, as conducted and reported here, answers the research questions about

what end of life is, how end-of-life care choice is done, and how these affect the way people

relate to one another. The main contribution of this study is that it compares the lived

experience of 'end of life' and EOLC practice to the recent English EOLC policy discourse.

This has demonstrated that the key aspect of the policy – that dying is manageable through

individual choice – is conceptually fraught when death is unpredictable and choice is not

autonomous (see Chapters 3 & 4). Instead, I have established how 'end of life' is not

experienced as a period of decline or liminal state, but that the waiting and ways of relating

people experience resemble other times of their lives and extends 'dying' into living (see

Chapters 6 & 7). Additionally, I have highlighted the relational nature of creating EOLC

choice, both in terms of how preferences are determined within practice (see Chapters 4

&5)and how people formulate such decisions based on their relationships with others (see

Chapter 6). By focusing on relationality, this study emphasises the importance of

relationships in terms of maintaining personhood and suggests that such an approach

counters the individualistic nature of end-of-life care choice and concerns about social

death. Lastly, rather than presume that choice is opposed to care, by acknowledging that

choice within English EOLC is an attempt to respect personhood, 'doing choice' becomes an

expression of professional care and expressing choice informed through one's relationships

is informative of the network of care one is part of. Therefore, whilst policy's premise that

individual choice leads to a manageable, good death is problematic, taking a relational approach suggests that it is not devoid of care or personhood, although these may not be located within the practices idealised by policy.

The study is not without limitations through. Since many long-term participants, who could have been in their last year of life, outlived the fieldwork stage and patients deemed to be 'actively dying' were shielded during clinical shadowing, I was unable to observe and learn as much about 'the end' in 'end-of-life care' as I had previously anticipated. In fact, death is oddly absent in most of my notes and as discussed previously, the lengthening of what 'the end' in 'end of life' means problematizes how much EOLC is about death and dying. For those seeking answers about how 'choice' plays out at the moment of death, this study cannot provide direct data on the subject. Instead, it focuses more on how end of life, dying, and the dying person are constructed and how 'choice' is made meaningful in this designated life period.

The ethnographic approach adopted here was intentionally broad and flexible in an attempt to capture things as they unfolded. This scope, however, carries with it the likelihood that certain events may only be witnessed once, or not at all, and many of the stories are highly individualised. Due to the nature of the research questions and the small 'sample size' I have not attempted to make any quantitative statements about the data or to generalise in this way. Ethnography provides an interesting dialectic and dilemma between the specific and the general. For this reason, in the analyses I have emphasised that it is the interpretation and meaning derived from experiences – rather than the exact experiences themselves – that are potentially generalizable. This is where moving beyond description to theorising helps makes sense of the data available in a way that, regardless of

the bounded context of a study one can make statements that may extend beyond that context.

It is important to remember the context of the study, based on in a specific locality within England from 2010-2013. The study included people of different ages and backgrounds, who had different health conditions; this allowed for certain commonalities beyond these 'variables' to be discussed. I cannot comment on any ethnic or cultural variation within England as the data does not support such claims. Similarly, most of the participants had families and all of the long-term participants had children; the extent to which discussions in Chapter 6 would apply to those without such relations is unknowable given the present data.[67] Whilst the experiences discussed were valid for those in the study, I do not claim that they are representative of all of those who could be nearing death or that the practices observed are universal throughout the country. Yet, by being able to talk about issues like personhood, I have demonstrated how the issues raised link to a more fundamental nature of being.

No single research project can answer all the questions posed by a topic; the following questions are not addressed in this study but are related to and arose from the current project. Firstly, I was asked as part of my interviews and observations with policy makers: 1) what choice do people really want, and 2) how can we make advance care planning and EOLC better. Neither of these were the direct focus of this research and any response would be bounded by the context of the project and an inference. Rather than directly address these concerns, I have sought to unpick the various notions on which they rely, further

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[67] Grande *et al.* (2009) indicate that caring for people in their own homes relies heavily on informal carers, often family members, and that such care is available is implicitly assumed within healthcare policy and practice. Clarkson *et al.* (2006) have demonstrated that people with dementia who have no informal carer or are widowed are more likely to be admitted to a care home. More research is needed to understand the role of relationships in these situations and how people experience dying without family or informal carer support.

complicating the ability to provide a neat response. This does not mean that I am not concerned with the answers, but rather I wish to further understand the underlying nature of the issues before pressing for the furthering of them.

For this reason, I suggest investigating the moral aspects of EOLC policy and practice. I tested the water with some of these ideas in Chapter 3 and in my reflections in the previous sections. These could be examined further in order to determine to what extent – and to what effect – policy is creating new norms for dying and the foundation of the values. This is particularly pertinent since such determinism seems paradoxical given the rhetoric of 'choice', although it has been acknowledged that modern society forces people to do nothing besides continuously choose and work on the self (Giddens 1991). Such research could engage with an anthropology of virtue and revisit the notion of 'good' death. On a practical level, this kind of analysis would suggest to what extent current standards reflect a wider social stance towards death or if it is creating a new dying script (see Seale 1998). In turn, this has implications for how English society and individuals within it are evaluating life and death.

An additional area ripe for additional exploration is the practice of imagining the future, both in terms of 'planning' and preparing for death. Whilst I have discussed how past experiences, the context of planning discussions, and the material used to aid advance care planning can influence what 'choices' are expressed, the role of imagination could be investigated further in terms of how this shapes practices and relations.[68] Adam (2010) has done interesting work similar to this in terms of ageing, but looking at dying could extend this analysis and discussions about time, the temporal order, and the role of reflexivity in

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[68] Ellis (2012) has explored some elements of this in her work on doing families in care homes.

current society (see Rose 1999; Arnason and Baldur Hafsteinsson 2003; Hockey and James 2003). As part of this, the symbolic aspects of imagined futures may illuminate what values are important to people at the end-of-life. This could be particularly productive when considering why elements of place are evoked when discussing preferences.

Similarly, the issues of 'waiting' and the problems this poses to conceptualising 'the end' and transitions could be further articulated. In particular, it could be fruitful to explore the phenomenological aspects of 'waiting' and the relation this has to people's existential experiences and beliefs. Part of holistic palliative and end-of-life care is to address the psychological and spiritual aspects of a person's life. This could be done through a discussion of waiting that does not emphasise models of grief or awareness of dying (c.f. Kübler-Ross 1967; Glaser and Strauss 1965), which focus on transitions, but rather the everydayness of 'being'. This could have implications for how death is treated discursively and in practice, shaking the shadow of crisis and 'journey' currently presumed in EOLC discourses. If dying is reframed as just another aspect of being and life, this may have more profound effects of shifting the 'death taboo' (Walter 1994; Zimmerman and Rodin 2004) than merely talking about death may do as discussion does not always serve to normalise subjects (c.f. Rose 1999).

The main strengths of this study are its ethnographic approach and focus on relationality that have demonstrated the differences between English EOLC policy discourse and the experiences of practicing and living at the 'end-of-life'. Whilst this methodology allows analytical generalisations, the generalisations are bound to the context of the research and do not directly answer any policy-related questions of how to improve end-of-life care. By exploring the differences in discourse and experience, I suggest that research in this area

could be furthered by investigating the moral nature of policy, how futures are imagined, and the phenomenological nature of being through waiting. Overall, this research indicates that choice in relation to English EOLC is more complicated and complex beyond the ability of individual autonomy to manage the dying process.

8.7: Conclusion

English end-of-life care policy views dying as a linear process of bodily decline that can be identified and managed through advance care planning, where patient choice is paramount in determining care arrangements. However, choice and 'end of life' are both discursive constructs. Whilst they are useful in mobilising health services around the goal of 'good death', they do not capture the experiences of persons that are considered to be in this category. By exploring the ways in which such an approach to dying has shaped the way care is delivered, I have illustrated how choice is used to represent care. Yet a more relational approach to understanding care demonstrates how relations play an integral part in maintaining personhood at a time when it is considered to be threatened by death. The main contribution of this study is that is demonstrates the disjuncture between how policy depicts 'end of life' and how it is experienced, and I have argued that this is mainly due to shifting the focus on relations rather than the individual.

9: Concluding Remarks

I began this research perplexed by how 'choice' could be a possibility – even a solution – when thinking about death in terms of managing the end of life. I have purposely not engaged with the discourse of choice as used within assisted-dying debates, as this has been well documented elsewhere (e.g. Hausmann 2004); instead, I have sought to understand how relatively new healthcare policy could make sense of death and dying through patient choice. I was also interested in how this approach shaped the way people experienced the end of life, however this may be understood. I took an intentionally broad ethnographic approach in order to set the healthcare policy interests in choice and end of life against healthcare practice and people's everyday experiences. In this I sought to understand when choice and end of life became present, how they were done, and how these concepts informed interactions. During fieldwork, I was shocked at how frequently neither choice nor death were explicitly present and struck by how unremarkable and ordinary the days and concerns of many of the participants were. I do not mean to suggest that they were not worried about their futures, noticed how their illness was changing, or that healthcare professionals were not actively doing advance care planning. These were just part of a larger picture of living, and it was through this lens that the importance of interaction and relationality became central. As such, in this dissertation I have sought to illustrate how the conceptualisations present in English end-of-life care policy are not necessarily represented in the ways in which choice is navigated and how people experience being in the abstract category of end of life.

Overall, English end-of-life care is constructed as the management of dying through respecting a person's choice about their death. Since the process of dying is not controllable, and choice not individual, the end-of-life care pathway presents an ideal rather than how care is practiced and this period is experienced. In this study, people were generally not planning for their deaths as policy suggests; they were navigating their social relations and day-to-day living. Rather than emphasise the importance of the individual in terms of understanding a good death, a relational approach allows one to appreciate the wider context in which life is made meaningful. Focusing on how personhood is understood through relationships rather than individual autonomy, has the potential to broaden the sense of 'care' encapsulated in end-of-life care and make it truly person-centred by embedding patients in their wider social networks and concerns.

Professional 'knowledge' for personal situations

Late 2012

Blink. Blink. Blink. The cursor's flicker taunts me. Surely a message from a dear friend written with such urgency and faith deserves a response. But the blank screen reminds me that I don't know what to write. "I'm sorry" soon stands alone. I've never liked the phrase as it pertains to death – it feels inadequate and vaguely selfish. All I'd like to do right now is share a cup of tea with her and listen; we always put the world to right with a bit of cake.

I re-read her message. She sent it over Facebook one evening. It starts with the usual "how are you" – it feels so normal. Then "I need to ask you a favour…to do with end of life care…I feel you are sort of an expert in it…and I need your help". I sense the screen darken as I read this.

Oh that sinking feeling – an expert? Who me? What information may I have from my research that could help her now? Yet somehow, I feel as a friend who supports me through the daily tribulations of doing a PhD she has a legitimate claim to the 'knowledge' 'it' produces. But what is that knowledge?

I read her message again. Her grandfather's rapid demise, swelling, difficult breathing. Troublesome hospital care and pesky bed sores. She worries about him, and her Nana. What will her Nana do? How can they possibly cope? Importantly, she tells me that she wants him to be living with, and not dying from, cancer even if it is

only for the next few months. Of all friends, I expect her to know as much, if not more

than, I do about dying and EOLC - as a medical student and former hospital employee

she's had more exposure than I could even seek out within my fieldwork. And yet,

here I am, positioned as the expert and friend, left to advise and counsel. Her

message is full of detailed questions about care plans and the way 'the system'

works. I begin to tease them apart and create structure in the chaos. I try to supply

her with the "insider info" she's requested.

Hours spent talking to people boiled down to telling another how to navigate the

system. Where do things like 'personhood' fit in here? Out of focus as the emphasis is

to relate. His life is made meaningful in our attempts to understand how to make his

dying better.

Image 13: A chair I often occupied during fieldwork – my 'position of knowledge'.

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Appendices

Appendix 1: Glossary

Acronyms:

ACP – Advance Care Planning

ADRT – Advance Decision to Refuse Treatment

COPD - chronic obstructive pulmonary disease

CPR – cardio-pulmonary resuscitation

DH – Department of Health

EOLC – end-of-life care

EOLCS – end-of-life care strategy

GP – general practitioner (doctor)

GSF – Gold Standards Framework

LCP – Liverpool Care Pathway

NHS – National Health Service

PPC – Preferred Priorities of Choice (document) or sometimes referred to Preferred Place of Care

PPD – Preferred Place of Death

PPI – Public and Patient Involvement

R&D – Research and Development

REC – Research Ethics Committee

Medical Concepts:

Advance Directive – A document that outlines what kinds of treatment/care a person does not wish to receive. May outline conditional situations when this applies

Biomedicine – clinical medicine that applies the principles of natural sciences, especially biology

Care Plan – to be devised between patient and care practitioner about the management of (long-term) health condition. Either a separate document and/or recorded in patient notes. Can also refer to the course of treatment/care to be provided by healthcare or social care professionals, including routine tasks, which may not have been discussed with the patient

Carer – paid professional that provides personal care to a person OR unpaid/informal carer who is often a relative, friend or family member that provides personal care. Often used to denote the latter

Clinical – relates to the observation and treatment of patients

Diagnosis – identification of illness/disease through physical examination, which can involve asking the patient about their symptoms

End of life – any time between last hours to last 12 months of life. For policy purposes, the last year of life represents the end of life

End-of-life care – care of patients whose disease is not responsive to curative treatment and they are likely to die within the next year

Evidence-based medicine – an approach to practicing medicine that aims to use scientific and population-based studies to inform clinical practice

Generalist – healthcare professionals trained in a broad field of medicine. Term is used typically to refer to general practitioners (doctors) and community/district nurses

Holistic – an approach to care that seeks to deal with the physical, psychological, social and spiritual elements of a person's illness

Hospice – can refer both to a model of care (based around palliative care) and/or a location were such care is delivered

Palliative care – aims to prevent and relieve suffering, including physical, social, psychological and spiritual suffering, to people and their families when a person is considered to have a life-threating illness

Palliative medicine – medical treatment provided to relieve suffering for patients with life-threating conditions

Pathway – refers to medical guidelines on how to handle patient cases based on particular conditions/situations. Often includes the key elements of care to be considered

Patient-centred care – care and treatment that is based the patient's wishes, preferences, needs and values

Plan – detailed description of course of action to treat and/or care for a patient

Prognosis – describes the likely course of an illness, disease or condition with some indication of time-scale

Renal failure – condition when the kidneys are unable to excrete waste

Social care – range of services provided by local authorities (government), private organisation, and voluntary sector to help people with daily living. Often includes help with washing, dressing, feeding and/or assistance with using the toilet

Specialist – a person who practices one branch of medicine, often after extra training

Terminal – used to describe conditions that have no cure and are likely to end in death

Analytical Terms:

Affect – states of mind and body that are related to feelings and emotions

Agency – the capacity to act

Autonomy – freedom to act and self-govern

Biological death – when the body is physiologically viewed as dead and therefore unable to sustain life

Dividual - person is understood not as individual but as extending into other persons and things, continuously divided and recomposed through social practices (see Strathern 1988)

Emic – used to refer to how people themselves talk about their social and material world

Etic – used to refer to the analytical interpretation, often of emic categories

Good death – a death that is culturally viewed as matching an ideal image of dying. For example, death that is peaceful and pain-free. Definitions of what makes a good death vary across time and places

Liminality – state of being between two other states of being/statuses; often the middle part of ritual practices and rites of passage

Medicalisation – process through which conditions and practices are considered to come legitimately under the remit of medical treatment and care

Patienthood – status of being a patient, treated for a medical condition in relation to healthcare professionals

Personhood – status of being a person

Social death – where someone is socially treated as dead. Often involves the severance of relationships

Sociolization – process through which medicine incorporates social theory and social changes

Appendix 2: Examples of Project Forms

The following pages include the text of the participant information sheets and consent forms used for this study. The actual forms included university and National Institute for Health Research logos and were formatted to be user-friendly. All documents included the version number and date as required and approved by the research ethics committee.

Lay participants (i.e. patients and carers) were provided both a booklet (A5 sized) and a condensed explanation about the study (A4 size). These were informed by the patient and public involvement conducted in 2010. Policy makers and healthcare professionals were sent letters about the project.

Consent forms varied depending on the aspect of the study participants were part of. There were separate forms for the use of photography and for continuing the study in circumstances were a person may be unable to verbally express their consent (e.g. unconscious or sleeping due to a decline in their condition). Rather than include all versions of consent forms I have included the most frequently used version which was for interviews.

Text from one-page summary of the project for interview and long-term participants: Approaches to Care

I'm looking for several volunteers to help me with two projects about care and decision making. The projects aim to better understand people's experiences and current practice to help improve services. Project One involves a single interview lasting around an hour about your experiences of care and decision making. Anyone can take part in the interview.

Project Two is a longer study lasting up to a year. I'm looking for several people with different conditions and their close family/friends/ carers and relevant health and social care professionals to follow for a year to track their experiences of care and decision making. This can involve observations, interviews, photographs, and looking at medical/ nursing/care notes. Your level of involvement can be flexible and the study is designed to

suit those involved. It is likely that as part of this project you will see me at least twice a month.

   If you take part, it will not affect eth care you or someone close to you receives and you will not be compensated for your time. The study is aimed at improving future care experiences. People often find it helpful to talk about their experiences. Some people may find it distressing to talk about these issues. This is okay and I am sensitive to the matters at hand and will direct you to appropriate support if needed. Your participation is voluntary.

   If you are interested in taking part or want to know more, please contact me. Please read the information booklet for additional details about the study.

This form included a table of the activities involved in each project, a photograph of the researcher, and contact details.

Approaches to Care Participant Information Booklet (A5) for interview and long-term participants:

Introduction

I would like to invite you to take part in a research study. I am interested in finding more about care and decision making where you live. I will look at decision making and care in different places for different people. Understanding what is important to people, how decisions are made and local practices will help us design better services in the future.

   Before deciding, it is important you know why the research is being done and what it involves. Talk to others about the study if you wish. I am happy to go through this information with you and answer any questions you might have. My contact details are at the end of this leaflet.

How can I help?

I am looking for volunteers for two projects.

1.   The first project involves an interview only.

2.   The second project is a long-term study. The researcher will follow people for up to a year. This involves interviews and observing the care in different settings.

Why have I been invited?

You have been given this information because:

•   you are someone interested in the study

•   someone else has suggested you might be interested in the study

•   you are a family member, significant other, friend or carer of someone interested in the study

I am asking 20 people to meet me and discuss their experiences of care and decision making. Anyone can do an interview if they want. This is for the first project.

For the second project, I am looking for ten people with a variety of health conditions to help. The study will involve observations and interviews over several months. With the person's agreement, people involved in their regular care will be asked to help. This can include family members and healthcare and social care professionals.

Do I have to take part?

No. It is up to you to take part or not. If you decide to take part, you are free to withdraw at any time. You will not have to give a reason. This will not affect the care anyone receives.

What will happen if I decide to take part?

 If you would like to join the study or would like to know more, please contact me. I will phone you to answer any questions you may have. If you decide you would like to take part, please return the reply sheet. Your GP may be contacted. The decision to take part is yours. I will arrange to meet you to fully discuss what we will be doing. I will also ask for your

written agreement. This meeting will be at a place and time that is convenient to you. I may also ask to meet family members, friends or carers. This can be at the same time or separately.

1.   Interview-only project: After the initial meeting we will arrange a time and place for the interview. You can decide if you would prefer to be interviewed alone or with someone else. Everyone who is interviewed will be asked to give their written agreement to be interviewed.

Interviews should last about an hour for each person. With your permission, some might be longer. If you agree, interviews will be audio-recorded. You will be paid for any travel to and drinks during the interview.

2.   Long-term project: I will regularly visit you. With your permission, I will observe, the care that people receive in many different settings. This can include where you live, consultations with GPs, and visits to the hospital. What this is will vary for each person and you can discuss this with me prior to starting the study. The study will last up to 12 months and we can discuss the amount of contact and involvement you have with me. For example, I could visit you once a fortnight for several hours.

I may ask your permission to contact your GP, specialist nurse or other regular healthcare and social care professionals. This is so they can be involved in the study. I may also ask you if I can look at your medical, nursing and/or care notes. You do not have to agree to every part to be in the project.

As part of the second project, I may ask to talk to you about your experiences of care and decision making. This is to help me understand your point of view. It might be helpful to do this several times over the course of the study. Sometimes I will ask you if I can audio-record our discussions.

You might also be asked if I can take a photograph. This will be of you or the place you are in. I will use the photographs in my reports. You can have a copy if you want. Everyone in the photo will be asked to confirm that they agree to me using the photo.

This table lists the different activities in the projects. You will be asked for your consent for each activity. You can take part in either project.

Interview-only Project	Long-term Project (up to 12 months)
One interview, lasting about an hour	Multiple visits by me to place of residence and/or care
	Several interviews over the study period
	Observations of consultations and visits to clinics
	View patient's notes
	Photographs

In some cases, I will also ask you to review initial ideas and findings from the study.

What are the possible disadvantages and risks of taking part?

Sometimes talking about care and health issues can be upsetting. We can talk about this when we meet for the first time and agree how to support you. If concerned, I will suggest you contact your doctor or nurse. If I am really concerned about your well-being I will contact them on your behalf.

What are the possible benefits of taking part?

Many people find it helpful to talk about their experiences. By better understanding care, decision making and practice I hope to improve people's experiences in the future.

What if there is a problem?

If anything about this study concerns you, contact me, Erica Borgstrom, or my supervisor Dr. Stephen Barclay (01223 763082).If you remain concerned you can contact the Patient

Advice and Liaison Service (PALS), who provide advice and support to patients, relatives and carers. Freephone: 0800 279 2535 or 01223 725588.

Will my taking part in this study be kept confidential?

Yes. All information given to me during the course of the study will be kept confidential. Contact details will be kept in a secured location. Interviews will be anonymised.

Names of peoples and places will be removed from the notes. You will not be identifiable in any reports that are written. Each person in the photograph will be asked if it can be used. Your GP may be notified about the study.

What will happen if I don't want to carry on with the study?

You are free to withdraw at any time, without giving a reason. This will not affect the care received or your legal rights. If you withdraw, I will ask you if I should destroy the interview notes and/or photographs. All other data gathered, such as notes from observations, will be kept and used by me.

What happens to the information I give?

What happens to the results of the study? Your experiences and views are a key part of this research. I will carefully analyse notes from observations, the interviews and the photographs. This is so I can better understand care and decision making in different places and for different people. A report will be sent to the funders of the research and to local NHS services. I will also present the findings to NHS service providers, at conferences and publish them in journals. Those findings will be the main part of my student project for the University of Cambridge. You will not be identified personally in any report or publication. You can also have a summary of the report.

When we meet I will ask you if you would like me to send you one. It will probably be ready a year after the study has finished.

Who is organising and funding the research?

This study is funded by the Collaboration for Leadership in Applied Health Research and Care (CLAHRC) in Cambridgeshire and Peterborough. It is supported by the University of

Cambridge. It is led by Erica Borgstrom. She is a student at the University of Cambridge. Her academic supervisors are Dr. Stephen Barclay and Dr. Simon Cohn.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people on a Research Ethics Committee. This study has been approved by Committee 3 in Cambridgeshire. It has also been reviewed by several groups of academic and healthcare professionals and service users.

Key Information:

- This study is to understand care and decision making.
- It is taking place in Cambridgeshire and Peterborough.
- Many different people will be taking part.
- There are two projects.
    - Interview only
    - Long-term study with observations, interviews and photographs.
- It is your decision if you want to take part and whether you would like to do an interview only or both interviews and long- term observations.

Booklet also contained contact details for the researcher, a photograph of the researcher and the appropriate logos.

Example of letter sent to healthcare professionals and policy makers:

Dear [Professional],

Approaches to Care

My name is Erica Borgstrom. I am a PhD student in the Department of Public Health and Primary Care at the University of Cambridge. I am conducting a research study as part of the requirements of my PhD degree, and I would like to invite you to participate in an interview about choice and end of life care in the UK.

I am studying issues of choice in relation to end of life care in the UK. This is to understand better what choice is, how it affects end of life care, and the policy around these issues. You have been invited because of you are a professional involved in end of life care. If you decide to participate, you will be asked to meet with me for an interview about these issues.

The meeting will take place at a mutually agreed time and place, and should last about an hour. With your permission, the interview will be audio recorded so that I can accurately reflect on what is discussed.

Interviews will be transcribed and anonymised. All copies will be kept securely – either on encrypted computer drives or in locked filing cabinets at the University to which only I have access. Participation is confidential. The results of the study will be published and presented at professional meetings, but your identity will not be revealed. A report will be sent to the funders of the research and to local NHS services. If you would like a copy of any report or publication, please let me know.

For various reasons, some people may feel uncomfortable discussing some of the issues. You do not have to answer any questions that you do not wish to. Although you probably will not benefit directly from participating in this study, this study aims to improve end of life care on a local and national level. Taking part in the study is your decision. You do not have to be in this study if you do not want to.

You will be reimbursed for your time and any travel expenses. These will be sent after an invoice has been received. I will give you the invoice at the interview.

This research is funded by the NIHR Collaborations for Leadership in Applied Health Research and Care for Cambridgeshire and Peterborough and my academic supervisors are Dr. Stephen Barclay and Dr. Simon Cohn. This study has been reviewed by a research ethics committee and several groups of academics, healthcare professionals and service users.

I will be happy to answer any questions you have about the study. You may contact me at 07580785231 or by e-mail at eb442@medschl.cam.ac.uk.

Thank you for your consideration. If you would like to participate, please complete and return the attached reply sheet or contact me using the details provided. We can then arrange a time and a place for the interview.

I look forward to hearing from you.

Kindest Regards,

Erica Borgstrom - PhD Student, University of Cambridge

*Letter was signed, dated and on University/CLAHRC headed paper.

Example of a Consent Form: Interview Consent

Approaches to Care

Participant Consent for Interview Version 2.1

Please initial box
if you agree

1. I confirm that I have read and understood the information sheet for the *Approaches to Care* study. I have had the opportunity to consider the information, and ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withdraw at any time. I do not need to give a reason. It will not affect the healthcare I receive or my legal rights.

3. I agree to the researcher informing my GP about my involvement in the study.*
Not relevant for interviews with healthcare, social care and policy professionals.

4. I agree that the information collected during the study may be audited by officials from the research funders or the University of Cambridge.

5. I agree that audio recordings can be made of interviews with me and understand that what I say may be used anonymously as part of a final report and publications.

6. I agree to take part in an interview as part of the *Approaches to Care* study.

_____   _____   _____

Name of participant   Date   Signature

_____   _____   _____

Name of researcher   Date   Signature

One copy for the participant, one copy for the researcher.

Appendix 3: Overview of Methods

This section includes an overview of the details of data collection and data analysis.

Overview of Interviews and Observations:

Policy:

- 12 formal interviews with local and/or national policy makers
- 7 observations of policy-related events

Health-care practice:

- 34 observations in hospitals, hospices, or GP practices; additional observations in community settings (e.g. support groups that included had a nurse present)
- 14 formal interviews with healthcare professionals (2 GP; 1 consultant; 3 Macmillan nurses; 2 district nurses; 3 hospice workers; 3 other specialists)

One-off semi-structured interviews with patients and carers*:

- 22 interviews with patients
- 16 interviews with carers
- 5 interviews with couples (patient and carer)

Long-term participants:

- 10 people, 4 of which had spouses/partners regularly involved in the study and 2 of which had adult children that I interviewed
- Included over 100 observations/visits and additional contacts (phone calls, emails, letters) ranging from 4-25 visits per person

*The categories of patient and carer are based on how the person presented themselves at time of recruitment. See section 6.4 for how these categories can be blurred.

In this document, references to *some* equate to approximately a third of the sample and *many* to three-quarters or more.

Example of Interview and Observation Guides

I include these guides for illustrative purposes; I tailored my questioning and observations based on the situation and persons I was with and added questions in response to what people said.

Policy interviews:

- Personal background
- Involvement in palliative care – past and present
- Involvement in policy-making/changing
- Important aspects of EOLC policy
- Advance care planning and choice
- Future directions of policy

Healthcare professional interviews:

- Professional background
- Role in palliative care/EOLC and/or particular patient's care
    - If relevant: background to patient's case and check future questions both generally and in relation to patient
- EOLC more generally within clinical practice
- Advance care planning, choice and place of death
    - Use of any specific tools

Patient/carer interviews:

- Reason for wanting to take part
- Personal background
- Experiences – of care, of illness
- Examples of decision-making and thinking about the future
- If 'choice' mentioned, follow up

Observations:

- Use of 'tools' advocated in EOLC strategy
- Mention of 'choice'
- Involvement of patient/carers in decision-making and/or care planning
- Categorising patients/persons

- Care
- Hierarchy and relationships

Example of Fieldnotes

Fieldnote reference – name and date

Location of observation/interview

Time of observation/interview

If any audio or handwritten notes were taken; where these are located/reference numbers

Who was present

Summary: Here I write the intention of the visit/observation/interview and an overview of the session.

Main body: Here I write a chronological account of the observations and discussions. This includes not only what was said, but how it was said and how people interacted with one another and objects. I try to include as much detail as possible, including what the setting was like.

Comments: In this I may include a second overview, which begins to inform the analysis as I start to think about what topics are of interest and where the subjects may be going. I include notes on items or themes I want to explore further, either with the same people/places or in other contexts. In my field diary I include notes on how the sessions made me personally feel.

Keywords: I often tag several key words so that I can re-find notes more quickly later on and so similar notes are grouped together. This often includes topics of conversation or who/what the note is about.

Overview of Analysis:

Fieldnotes were written for all encounters as well a separate notes in a field diary that were more personal and reflective. Several interviews were transcribed verbatim to get a feel for the content, but most were left as audio files supported by fieldnotes and only transcribed when key passages and direct quotes were needed. All forms of data, where possible, were stored in Evernote (software programme) so multiple files could be examined at the same time and easily cross-referenced by myself.

  Analysis was an iterative process. As prominent or interesting issues arose, I wrote memos (also stored in Evernote) about the topic. Information in memos included when topics became apparent, the context they were used in, my thoughts on when, why, how and to what extent these issues were important and related to other issues, other notes, or previous literature. These notes continued as I conducted more observations and interviews and as I re-read and reflected on the data already gathered. I did not formally code the data in a programme, like NVivo, as I sought to keep the analyses in relation to the context as much as possible rather than extract discrete pieces of text. The memos then formed the basis of the initial sketch of my ideas for the dissertation, develop the theory included, and helped shape the content of the chapters.

Appendix 4: Key Informant Summaries

This section provides a brief outline of key informants referred to in this research. Many more people were interviewed, including some who were part of the longitudinal study, but for the purposes of brevity and coherence I have chosen to focus on fewer stories. Elements from other interviews and encounters echo the sentiments and statements contained here and in some sections, in this dissertation I have deliberately woven stories to enable the interpretation. All names used here are pseudonyms and I have changed conditions (or left them intentionally vague) to help protect participants' anonymity.

Albert

Albert has been living in a care home since being diagnosed with vascular dementia two years ago. Unlike many of the other residents, Albert was able to care for himself most days and could hold lengthy conversations; however, he felt very lonely and missed his family who did not visit him. In spite of being in his 80s, he readily revelled in how he was a good sportsman and was on the lookout for a new (and much younger) partner.

Alfred and Vera Ward

Both in their mid-70s, Alfred and Vera characterised their current situation as one that has lasted for the best part of a decade, since Alfred's diagnosis of a degenerative neurological condition which is "slowly shutting his body down". He required the use of a motorised wheelchair and their bungalow was adapted for his condition; Vera did much of the housework and was his "carer" although she had cancer several years ago. They were

happily married, recently celebrating a big anniversary, and were proud parents and grand-

parents. Although they did not live close to all of their children, they had regular contact

with them. The Wards continued to socialise and often had friends around for dinner and

Vera jetted off on holiday with several friends every year. Alfred's humour was infectious,

matching his jolly characteristics, and he would frequently kid Vera, who both laughed with

him and worried about him.

Barbara

Having previously smoked for many years, Barbara was not surprised that she had COPD

although it had lasted for years with no avail. She was very self-conscious of her coughing

and the illness-induced weight loss and tried self-management as much as possible.

Widowed and living alone in sheltered-housing, she was one of the younger residents in her

area being in her 60s. She had previously been politically involved and her active mind

continued as she expressed her views about local and national policies. She remained

thankful and committed to the NHS even after several "run-ins" with the system, which

resulted in frustrations and infections, and was always willing to persevere.

Chris

In his mid-fifties, Chris was the youngest of the long-term participants. His cancer diagnosis

came as a shock to him and his family, leading to a series of "crises" including sudden

unemployment, rising debt, and losing their family home. Self-described as working class, he

resented the apparent idleness that the combination of illness and no income created for

him. He often dreamed about what else he could do with his life and what he would do

when he got better, although he also realised that he may not recover. Chris was very family focused and often spent time talking about his family and visiting his elderly parents.

Christina

Sprightly and well-kept, one would never guess that Christina had had four different cancers within the last 10 years and was often unwell due to the consequences of all the treatment. Now in her mid-sixties, Christina kept busy visiting friends, helping her daughter with the family business, and going to various medical check-ups. During the course of the study she was not receiving any active treatment for the cancers, but was regularly monitored and feared they could come back or a new one would surface. Despite her parents living into their 90s, her brother had already died from cancer and she doubted she would make it as long as them, although many healthcare professionals commented on her "miraculous and surprising" ability to survive. This was put down to her "get-up and go" attitude.

Mable

Mable was a regular at her cancer support group and was known for her smile. Quiet and obliging, she did not complain and was a "good patient" when in hospital. She frequently told stories about her late husband, of whom she had a photo of in her purse to show as part of her romantic tales set in the Indian sub-continent. She lived an international life but felt settled in England, mother of two sons. Mable died in her mid-80s during the course of the study after several weeks in hospital as doctors sought to understand "why she wasn't doing so well", as she put it.

Oscar and Pamela

Barely of retirement age, Oscar did not see himself as "old" in his 60s and he loved to philosophise about life. Struggling to find a diagnosis for his degenerative condition at first, he was classified as having a "rare and slow progressing disease" which affected his mobility and would later likely affect his breathing. There was as much certainty and uncertainty with his condition and he often worried about "who would go [die] first" – him or his wife – especially given how much he relied on his wife. As a retired nurse, Pamela tenaciously took on his "care needs", even when this was physically demanding. She regularly cared for him in medical settings as well, willing to be a "bulldog to fight for him" when they saw fit as care services failed to meet their expectations. Wishing to maintain their independence, Oscar and Pamela carried on with daily life as best as they could and their house seemed to be under continual adaptation to suit Oscar's changing needs and to address concerns they had about his safety. Their children and grandchildren visited occasionally and one particular relative was especially concerned when Oscar was later diagnosed with a rare cancer on top of his "other condition".

Rosalind

Nearing 100 years old, Rosalind frequently told me she had lived long enough that I should "clap and praise the Lord" when I heard she had died. She had breast cancer which she had left untreated but did not complain of this. She had troubles with her sight and hearing, which was attributed by her and others as "old age". Rosalind was often the centre of attention and these "complaints" added to her loud character and charm. She had recently moved several hundred miles to be closer to her daughter, Sara. As her main visitor, often coming daily, Sara encouraged her mother to continue her hobbies although Rosalind complained in jest that the "gremlins hiding in the house" often played tricks on her making

it difficult for her to do these things. She later moved to a care home when Sara noticed

that Rosalind was no longer willing or able to do be involved in the social activities her

previous home offered. She died in the care home a few months later.

Appendix 5: Supportive and Palliative Indicators Tool (SPICT)

Supportive and Palliative Care Indicators Tool (SPICT™)

NHS Lothian

www.spict.org.uk

The SPICT™ is a guide to identifying people at risk of deteriorating and dying.

Look for two or more general indicators of deteriorating health.

- Performance status poor or deteriorating, with limited reversibility. (needs help with personal care, in bed or chair for 50% or more of the day).
- Two or more unplanned hospital admissions in the past 6 months.
- Weight loss (5 - 10%) over the past 3 - 6 months and/or body mass index < 20.
- Persistent, troublesome symptoms despite optimal treatment of any underlying condition(s).
- Lives in a nursing care home or NHS continuing care unit, or needs care to remain at home.
- Patient requests supportive and palliative care, or treatment withdrawal.

Look for any clinical indicators of advanced conditions

Cancer

Functional ability deteriorating due to progressive metastatic cancer.

Too frail for oncology treatment or treatment is for symptom control.

Dementia/ frailty

Unable to dress, walk or eat without help.

Choosing to eat and drink less; difficulty maintaining nutrition.

Urinary and faecal incontinence.

No longer able to communicate using verbal language; little social interaction.

Fractured femur; multiple falls.

Recurrent febrile episodes or infections; aspiration pneumonia.

Neurological disease

Progressive deterioration in physical and/or cognitive function despite optimal therapy.

Speech problems with increasing difficulty communicating and/or progressive dysphagia.

Recurrent aspiration pneumonia; breathless or respiratory failure.

Heart/ vascular disease

NYHA Class III/IV heart failure, or extensive, untreatable coronary artery disease with:

- breathlessness or chest pain at rest or on minimal exertion.

Severe, inoperable peripheral vascular disease.

Respiratory disease

Severe chronic lung disease with:

- breathlessness at rest or on minimal exertion between exacerbations.

Needs long term oxygen therapy.

Has needed ventilation for respiratory failure or ventilation is contraindicated.

Kidney disease

Stage 4 or 5 chronic kidney disease (eGFR < 30ml/min) with deteriorating health.

Kidney failure complicating other life limiting conditions or treatments.

Stopping dialysis.

Liver disease

Advanced cirrhosis with one or more complications in past year:

- diuretic resistant ascites
- hepatic encephalopathy
- hepatorenal syndrome
- bacterial peritonitis
- recurrent variceal bleeds

Liver transplant is contraindicated.

Assess and plan supportive & palliative care

- Review current treatment and medication so the patient receives optimal care.
- Consider referral for specialist assessment if symptoms or needs are complex and difficult to manage.
- Agree current and future care goals/ plan with the patient and family.
- Plan ahead if the patient is at risk of loss of capacity.
- Handover: care plan, agreed levels of intervention, CPR status.
- Coordinate care (eg. with a primary care register).

SPICT™, June 2013

Appendix 6: Preferred Priorities of Care Document

Preferred Priorities for Care
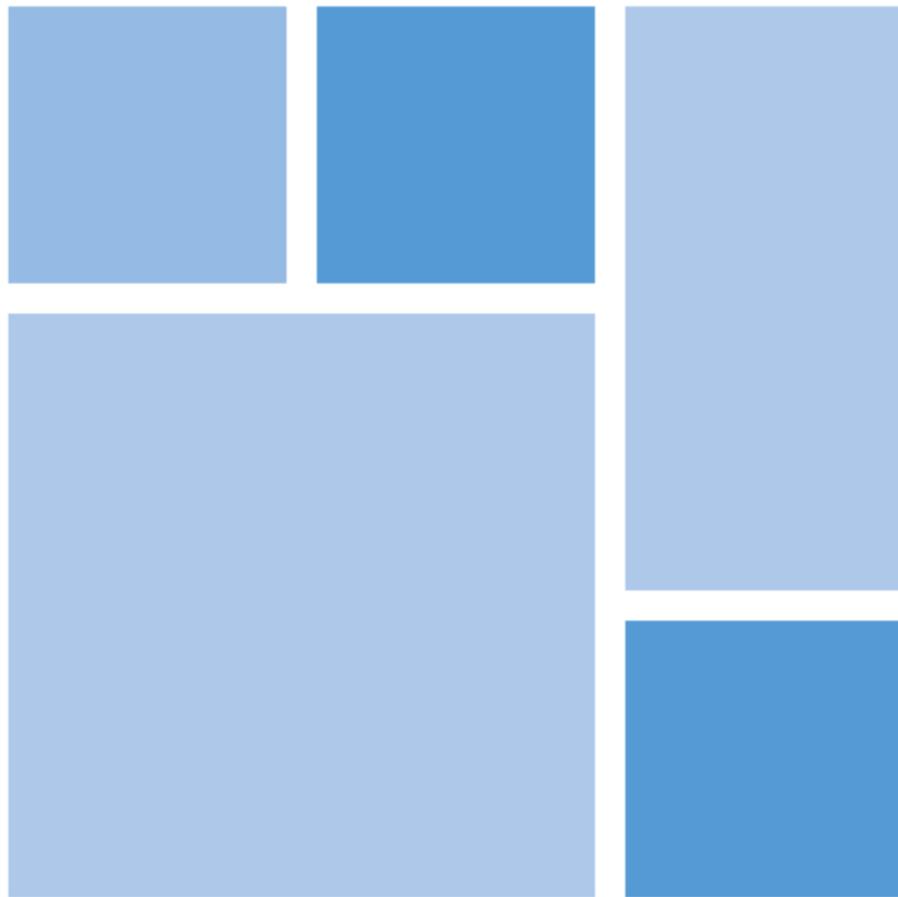
Preferred Priorities for Care

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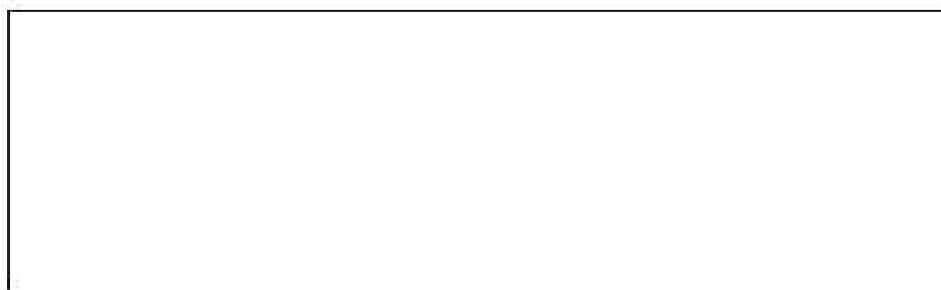
What is this document for?

The Preferred Priorities for Care (also known as PPC) can help you prepare for the future. It gives you an opportunity to think about, talk about and write down your preferences and priorities for care at the end of your life. You do not need to do this unless you want to.

The PPC can help you and your carers (your family, friends and professionals) to understand what is important to you when planning your care. If a time comes when, for whatever reason, you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will have to take into account anything you have written in your PPC.

Sometimes people wish to refuse specific medical treatments in advance. The PPC is not meant to be used for such legally binding refusals. If you decide that you want to refuse any medical treatments, it would be advisable to discuss this with your doctors.

Remember that your views may change over time. You can change what you have written whenever you wish to, and it would be advisable to review your PPC regularly to make sure that it still reflects what you want.

Should I talk to other people about my PPC?

You may find it helpful to talk about your future care with your family and friends, although sometimes this can be difficult because it might be emotional or people might not agree. It can also be useful to talk about any particular needs your family or friends may have if they are going to be involved in caring for you. Your professional carers (like your doctor, nurse or social worker) can help and support you and your family with this.

When you have completed your PPC you are encouraged to keep it with you and share it with anyone involved in your care. Unless people know what is important to you, they will not be able to take your wishes into account.

Will my preferences and priorities be met?

What you have written in your PPC will always be taken into account when planning your care. However, sometimes things can change unexpectedly (like carers becoming over-tired or ill), or resources may not be available to meet a particular need.

What should I include in my PPC?

You should include anything that is important to you or that you are worried about. It is a good idea to think about your beliefs and values, what you would and would not like, and where you would like to be cared for at the end of your life.

People who should be asked about your care if you are not able to make a decision for yourself

You may have formally appointed somebody to make decisions on your behalf, using a Lasting Power of Attorney, in case you ever become unable to make a decision for yourself. If you have registered a Lasting Power of Attorney please provide their contact details below.

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Name:

Address:



Telephone number:

Relationship to you:
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Even if you have not registered a Lasting Power of Attorney, is there anybody you would like to be consulted about your care in the event that you are unable to make decisions for yourself? If so, please provide their contact details below.

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Name:

Address:



Telephone number:

Relationship to you:
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Your preferences and priorities

In relation to your health, what has been happening to you?

What are your preferences and priorities for your future care?

Where would you like to be cared for in the future?

Signature   Date

Please record any changes to your preferences and priorities here
(Please sign and date any changes)

Further information

You can use this page to make a note of any further information you need or questions you might want to ask your professional carers (like your doctor, nurse or social worker).

Contact details

You can use this page to record contact details of anyone who is involved in your care.

Name	Relationship to you	Contact number
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This document was given to me by:

Name:

Organisation:

Tel:

Email:

Further information about PPC is available at: www.endoflifecareforadults.nhs.uk

Originated by Lancashire & South Cumbria Cancer Network June 2004 and endorsed by the NHS End of Life Care Programme

Revised December 2007 by the National PPC Review Team

V2.2/2011