

Death and Grief in Working-Class Communities:
Narratives of Recently Bereaved Carers

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A thesis submitted in partial fulfilment of the requirements of
Teesside University for the degree of Doctor of Philosophy

February 2020

Abstract

The sociology of death, dying and bereavement has sought to understand how social divisions, including gender and ethnicity, impact at the end-of-life and into subsequent bereavement. Despite the prevalence of epidemiological evidence indicating continuing health inequalities and a higher mortality rate for those from working class communities, this area has hitherto received little attention (Howarth, 2007b). This research seeks to address the dearth in understanding of the experience of end-of-life and bereavement in disadvantaged and working-class communities by undertaking a series of narrative interviews with bereaved carers in Teesside, UK. The findings illustrate that end-of-life and grief are complicated by many care, familial and non-death issues. These issues are not simply personal troubles but must be understood in a broader societal and cultural context in which bereaved carers have to respond to both overt (e.g. intervention by mental health care workers) and tacit (e.g. limitations for which grief is acceptably performed) social expectations about 'doing grief'.

Findings from interviews suggest a desire for 'normal' bereavement, however this was frustrated by complex circumstances (unemployment, criminality, mental health issues, substance misuse) and a perception that grief required justification against a prevailing, neo-liberal discourse of grief being shameful (Peacock, Bissell and Owen, 2014b), and an expectation that achieving acceptance and 'moving on' was required. These struggles make explicit a latent power struggle, which results in those whose social position is comparatively lower experiencing more difficulties in resisting perceived stigma and shame, based on their difference from healthcare professionals, and cultural beliefs and choices in bereavement. The narratives given by participants give examples of societal internalised oppression (symbolic violence), causing distress but also instances of resistance. The comparative absence of similar experiences of more affluent members in the sample, suggests that this hardship points to social class, shame and stigma being a determining factor at end-of-life and into subsequent bereavement.

Acknowledgements

I would like to take this opportunity to thank the many people who have helped me. Thanks to my colleagues at Teesside, Newcastle, and across the network of sociological meetings. Many of you have become close friends, and without your faith in me, we know my inner bully might've bloody won! Katy McEwan, Mwenza Blell, Kate Haddow, Ben Roberts, Ryan Kenny, you've all been there when I have needed a chat, a cry, a fry-up at Roy's, a removal service, a place to crash, and most frequently, a person to vent to. And thank you to Steve Scott-Marshall whose validation saw me through the difficult times. Thank you to my family. All variations of McKenzie's, Mulrine's and Earle's, it has been a pleasure knowing you are all supporting me.

My supervisors' insight has been so incredibly valuable throughout this process. But Dr Peter Van Der Graaf, if you hadn't picked up the torch as Director of Studies #4, with your relentless positivity and unwavering belief in me, well, I wouldn't be writing this.

David "Hilly" Hill, for always feeding me well, and making me laugh when I needed it most, thank you. Note: this is not an admission that you are a comedy genius. But ta, mate, it doesn't go unnoticed.

My parents deserve special recognition. My Dad – the consummate angry, Marxist, Glaswegian – has shaped my analytic awakening in childhood, helped me be politically unapologetic, and shown me how not to acquiesce. My Mum – known to me as MacMac – is the source of all my empathy and compassion. She is my role model for strength, enthusiastic chattiness, and finding joy in listening and storytelling.

Lastly, but most importantly, I would like to thank my participants. Their warmth, sincerity and generosity were truly transformational. Beyond the personal insight and illuminating snippets of the lives presented here, you've passed on such strong feelings of care and kindness that it has changed my life. My time with each one of you will stay with me, and I am 'propa' grateful.

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Chapter 1: Introduction

1.1 Topic and Focus

Death has famously been referred to as ‘the great leveller’ by Mark Twain (1871), and Shakespeare’s *Hamlet* (1982) is thought to evoke how death is an “equaliser”. Yet beyond iconic figures of literature and the arts, it may well not feel like a leveller or equaliser for all. Evidence suggests the experience of dying and death is not the same for all. End-of-life and subsequent bereavement can impact in a variety of ways, for people from varied backgrounds (Wilkinson and Pickett, 2010). However, difference can be the clustering of distress or the symptomatic of a community of people bearing the weight of injustice. This thesis seeks to make the case that the literary notion of the great equaliser, hides a multitude of experiences, losses and harms.

Wright Mills (1959) described the “sociological imagination” as one that links the private problems of individuals with social issues. He stated the purpose of sociological endeavour was to understand “personal troubles” as “public issues”. In making this link sociology embraces a critical sensitivity and an emancipatory endeavour. This research is inspired by this, as the narrative accounts of participants must be understood in a broader societal and cultural context. The research will draw on a range of understandings in order to avoid a simplistic application of one interpretation which reflects the complex nature of the research matter itself.

Death is the event that is central to the focus of this thesis, by which I mean, that the unifying feature is that the consequences of dying and of bereavement are all bound up in death. It is a moment that all will experience. End-of-life, death and bereavement are parts of the life course that are simultaneously viewed as natural and pathological.

Grief has been the source of much interest, academically and culturally, with a long-standing interest from sociology. Critiques of some psycho-therapeutic models of bereavement have helped challenge the notion that there is one singular way in which to grieve, and for that grief to be resolved, in a healthy manner. But while there has been recognition in some circles of diversity in

grief and bereavement practice, in some respects this may not have yet filtered to the level of the individual.

Within funeral rituals, there is evidence of this reproduction of 'acceptable practices'. There have recently been a number of emerging examples; for instance, the governance of cemeteries and attempts to remove 'tacky' mementoes from graves (Levy, 2011; Johnson, 2016) . This could be considered an example of cultural reproduction, symbolic violence and normalisation of middle-class ways of dying.

The majority of sociologists who work in this field are keen to improve experiences of death and to challenge the power of professionals. Their work has thus developed a political agenda for change. But, in doing so, it has privileged middle-class interpretations of death in society and although gendered and ethnic differences are acknowledged and respected, the ritual and emotional experiences of working-class communities tend to be relegated to a lower division.
(Howarth, 2007b)

Briefly, I am aiming to evidence and make explicit a latent power struggle, which results in those whose social position is comparatively lower to experience more difficulties in resisting perceived stigma and shame, based on their difference from healthcare professionals, and cultural beliefs and choices in bereavement.

The argument is based on the findings from interviews carried out with bereaved carers. Additionally, the work seeks to address gaps in previous knowledge and extend the canon of the sociological understanding of death, dying and bereavement. The accounts given by a range of people living in the Teesside area pointed to a diverse range of experiences. What emerged was that a multitude of difficulties were experienced by some participants and a relative absence of similar difficulties for others. These 'difficulties' pertained to domestic violence, alcohol and substance misuse, addiction, criminality, childhood sexual familial abuse, inheritance disputes, mental health issues, physical health issues, kinship care of family, etc. Facing these

whilst also attempting to navigate care responsibilities for a family member who is dying, or in the grief of that loss, was described as being incredibly difficult. Traditional notions of 'doing grief' left some participants feeling as though they were abnormal or failing to 'accept' their loss.

Bourdieu (1998) argues that:

The function of sociology, as of every science, is to reveal that which is hidden. In so doing, it can help minimize the symbolic violence within social relations and, in particular, within the relations of communication. (p. 17)

It is this capacity for identifying and exposing hidden assumptions that give sociology its transformational potential. Some have applied his work to health-related areas (Williams, 1995; Holman, 2014).

1.2 Research Questions

In order to guide the research, the following questions shall be central to help interrogate literature, data and to present the findings:

- In what ways does social disadvantage affect the experience of people at end-of-life?
- Do differences in cultural practices and class-based resources prove significant and formative for those people in disadvantaged communities who are providing care for the dying?
- How does the carer from a background of disadvantage negotiate the differences in occupation, educational attainment and/or cultural status between themselves and the healthcare professionals with whom they interact in their role as a carer?
- Are these variations in background seen as significant by those at end-of-life and their care givers?

1.3 The Scope of the Research

Undertaking such a project, whilst ambitious in its scope, was limited by time and resource. The research was funded by the Foundation for the Sociology of Health and Illness and Teesside University and forms the basis of the completion of a PhD. Beyond this, it aims to add to the body of knowledge

more widely within sociology. Whilst, as will be discussed in greater detail, the interviews were initially guided by rough areas of discussion, the findings and themes that emerged were very much led by and a reflection of the experience of the participants.

The research focuses on the perspective of the bereaved carer and their experiences. It, therefore, does not attempt to or claim to present the perspective of the deceased, wider family, or friends. It also does not triangulate the perspective of a professional, practitioner or clinician view. By doing this, it allows the research to give the time and depth to focus on the important and previously overlooked accounts of those close to the event, who are also able to give an account of bereavement.

In attempting to recruit participants for a sensitive research topic, it was important that the research was inclusive and did not exclude potential participants based on particular measurements. As will be discussed later, this meant a range of participants and circumstances are presented here.

Given the focus of the research, the accounts of professionals involved with end-of-life, death, funerals, bereavement, support agencies, or arms of the state are not included. Whilst it may be of interest to triangulate the experiences of these professionals with the accounts given by those receiving the intervention, the remit of the research cannot extend to include this. The priority is to seek to explore the accounts of those who may otherwise be overlooked.

1.3.1 Research Setting: Why Teesside?

Teesside is an area that I personally know, and I believe to be different in many ways from the wider United Kingdom. However, it also has a population of people whose experience of social and economic fluctuation will be similar in many other areas of the country. In highlighting the demographic make-up of the region, the aim is to illuminate the reality of and keep pertinent the potential Teesside experience the research aims to explore.

Teesside is situated in the North East of England. The place name does not constitute a county but represents several unitary authorities. The research

draws upon the areas that make up Teesside, are Middlesbrough, Stockton-on-Tees, Darlington, Hartlepool and Redcar and Cleveland. It is important to understand the context in which the research takes place as it has several distinguishing qualities. In April 2016 these separate unitary authorities became the Tees Valley Combined Authority (TVCA), with a directly elected mayor for TVCA being voted for in May 2017. Throughout the research, the area will be referred to as “Teesside” (unless referring to the specific locale within), rather than “Tees Valley”. This reflects the more popular locally used phrasing (Hetherington, 2015).

The areas that border the river Tees, Stockton-on-Tees and Middlesbrough, are additionally surrounded by Hartlepool to the North, Redcar and Cleveland to the South and East, and Darlington to the West. The research scoped these unitary authorities. Whilst each of these towns make up the area of Teesside, they each have a set of defining characteristic and locally thought of s being fairly distinct from one another. However, they do share many features.

One such feature they share, as is the case for many regions throughout the UK, are neighbourhoods of affluence sitting alongside neighbourhoods of multiple deprivation. Despite the pockets of affluence, overall the Teesside area is one of the most deprived in the country, with many of the wards being classified as some of the most deprived in England.

I have grown up in Teesside, the child of two Glaswegians who moved to the area for work but through a variety of struggles found themselves unemployed and near destitute. Despite having a Scottish accent as an infant and much fondness for my spiritual homeland north of the border, I am also a proud Teessider. I grew up surrounded by trials and tribulations in my immediate community, and frequently my own household. It is home to me in many ways, and I can readily identify the social and cultural issues that have characterised the area, particularly since its mass de-industrialisation.

It has been noted that Teesside is often used as a case study site by academics interested in poverty, deprivation and disadvantage, and also a “policy lab” for politicians. The lives of people in the area have been used as

formative empirical evidence to challenge political rhetoric, with regards to the myth that there are “troubled” families in the UK where three generations have never worked (Macdonald, Shildrick and Furlong, 2014).

Whilst there has been concern levelled at undertaking sociological work in an area such as Teesside, given its rather unique history (Byrne, 1997) and present conditions, the need to explore, understand and represent the accounts of its residents is imperative. Lloyd (2013) contends that the area is, in fact, “representative of many other post-industrial towns and cities with nothing to offer” (p. 1). It is important to note and consider that the locality and circumstances may be viewed by some as exceptional, yet the accounts of those living in this area carry no less or more remarkable individual validity. In order to understand the wider societal issues, we must interrogate the individual and personal problems (Wright Mills, 1959).

1.3.2 Why Study Bereaved Carers?

The role of a carer can become an extensive and consuming set of responsibilities. Some may leave their job to undertake the role, suspend their own health concerns to prioritise others, or neglect other familial commitments or life events to provide care for a loved one.

When the person who is in receipt of care dies, the role of the carer ends. As with the death of a family member or friend a period of grief often follows. Yet for the carer their bereavement can be argued to be intensified. Firstly, the loss of the person for who they provided care would be severe due to the intensity of the time and proximity that the care relationship often generates. Secondly, at a personal level the carer could be described as not only going through the bereavement for the loss of their loved one, but also for their loss of role, purpose and identity.

To a certain extent the term for the population ‘bereaved carer’ has been hitherto little used. Those who have provided care and then no longer do, due to their death, stop being a carer and, therefore, stop being able to access the support agencies and services associated with being a carer. The carer support organisations involved with this project could readily point to

the number of carers they supported, but openly acknowledged that they had little conception of the numbers of bereaved carers.

I am interested in this thesis in the range of experiences and challenges faced by bereaved carers in the Teesside area, and to what extent these different signal latent power struggles related to social class structures and the norms that these structured force upon bereaved carers when grieving for the person they cared for. In short, I am applying a sociological lens to give voice to their private struggles and reframe them as public issues.

1.4 Definition of terms:

1.4.1 Bereaved Carers

This research uses the term 'carer' to refer to those persons who attended to a family member or friend with physical, emotional labour, of which they had to apportion time from their normal everyday activities, for which they may have been paid for (formal) or not been paid for (informal). By 'bereaved' the research specifically means that the person who is a carer is bereaved by the loss of that caring role and relationship by death.

1.4.2 Carers

The term 'carer' is often used but when, where and how a person becomes a carer is less obvious. Where do the tasks that someone may undertake as a partner or family member end, and the significant duties demanded by a carer begin? This was amended during the course of the research as the leaflets initially asked for carers. In changing the information the questions were asked if people undertook various duties and then indicated that by doing so that person may be a carer. This was important and when I interviewed people a number stated that they "did not feel like a carer" and that, what they did, was an extension of the everyday relationship they had with that person.

1.5 Situating Myself in the Research

I believe that I am myself part of the research and research process and not an objective bystander collating data. In light of this the pronoun will be used throughout the thesis as to implicate myself as a subjective part of the

research and learning process. Additionally, I believe it important to briefly describe myself in relation to the research, in order to help provide insight into the points of resonance to the topic, the findings, and most importantly the participants themselves.

I have a personal understanding of care and caring. My mother (affectionately known as McMac) became ill when I was a child. Previous to this she had been a single mother (for a spell of time) working long hours to build up flexi-time to take when myself or my brother were unwell or on holiday. For a long time, there was not a clear diagnosis and, despite her best efforts, she was declared disabled and could no longer work. I tried my best to help with housework and shopping as a child, and I feel I have known little else into my adult years. During my fieldwork this was shared; the care and consideration of my participants is unparalleled amongst any other social grouping I have known. I have 'chosen' to be geographically bound, and I currently live a 10 minute walk or 3 minute car ride (in emergencies) away from my mother. Her mobility has declined over the years and on our visits to our homeland to see our extended family in Scotland, I provide 24/7 hands on care. She rarely flinches in her chipper outlook, despite the chronic pain she has to manage, and she is always my biggest supporter and number one fan. I could not ever see her as different, difficult, or a burden. Our relationship is deep and special because of our circumstances. In doing this research, this has been reflected back to me, and that has been simultaneously solidifying, validating and devastating. I realise I am lucky to have her in my life.

Throughout this PhD there have been several difficulties in relations to my personal life and my academic life. To pretend that these things did not occur would be to misrepresent the research. My participants knew about many more of life circumstances than my fellow academic colleagues and it was a privilege to share with them, as they did with me.

Personally, I have had mental health struggles, considerable caring responsibilities for family members (notably my wonderful mother), had numerous house moves, family conflict, long-term relationship breakdown,

and during the fieldwork and write up my Dad was diagnosed with terminal cancer.

Academically, I have worked on numerous projects alongside my PhD and with many great and wise academics. However, it has been very difficult at times to support myself financially and a restricted income does not make for easy intellectual endeavour. Unemployment and underemployment have been challenging to work through. This does little to challenge the significant imposter syndrome that I (and many like me) struggle[d] with in the academy. When you are concerned that you were given this privileged opportunity to undertake a PhD because you are seen as working-class and that alone will buy you access, it is hard to not read the comments of “you are *lucky* to be here” as “you are a token/you are replaceable/know your place”. I worked in research in the academy prior to undertaking my research, and it is considerable emotional labour to deflect these issues.

Most importantly, I have had numerous changes to my supervisory team. Those involved with the supervision of my PhD over the time I have worked towards its completion are Dr Peter Van Der Graaf, Professor Rosemary Rushmer, Professor Janet Shucksmith, Professor Catherine Exley, Professor Paul Crawshaw, and Dr Steve Conway. Peter is my fourth Director of Studies and has been a huge help. Previously changes of supervisory team were due to differences of opinion, and resignation of post. These changes were sometimes a surprise to me and, whilst I am grateful for the support of the academics who came on board, I think all would agree that getting a new academic up-to-speed with your work, progress and perspective is a substantial task.

1.6 Thesis Structure

Having set out the impetus for this research and outlined the principal research questions, the following chapters will address the problem highlighted here. Chapter Two will review the literature. By discussing two bodies of academic research and sociological literature that have hitherto remained somewhat discrete, the literature review will identify gaps in understanding. The sociology of death, dying and bereavement will be

explored to give grounding in current knowledge. Following this the case will be made that, as evidence suggests stark inequalities in mortality rates, that there is precedent to consider the qualitative experience of this. Setting the scene with a discussion of social class, and what work has been done in the sociology of death, dying and bereavement to acknowledge class-based differences to date, the second chapter will conclude that there is scope for more work to be done.

Chapter Three will situate the research in terms of the research methodology adopted, and a consideration of why this is important. This chapter will then describe the details of the practical approach to access and recruitment, interviews and data collection, and the analysis of this data. Reflecting on the importance of reflexivity and my own position in the research will conclude this chapter.

Chapters Four, Five and Six will set the focus on describing the data and the themes that emerged from the fieldwork. Initially, the context of the lives and challenges faced by participants will be the given attention in Chapter Four. Moving on to Chapter Five, where the interactions with professionals, and particularly healthcare professionals will highlight incidences of frustrations with communication and access. The last of the findings, Chapter Six, will explore the manners in which participants approached funerals for the deceased, and then their sometimes difficult instances in trying to meaningfully memorialise their loss, and the judgement these actions brought upon them.

A discussion of the findings, how they related to the literature, and what can be interpreted and understood from these accounts will be the basis of Chapter Seven. Here there will be discussion of how the narratives given by participants give examples of societal expectations and internalised oppression where participants do not conform to those normative standards. Reflecting on the instances of distress and resistance, and highlighting the comparative absence of similar experiences of more affluent members of the population sample, the argument will be made that this hardships and

tribulations point to social class, shame and stigma being a determining factor at end-of-life and into subsequent bereavement.

Finally, Chapter Eight will revisit the content of the thesis, make recommendations based on the findings, and agitate for further research, advocacy and activism to be done in relation class-based experiences of death, dying and bereavement.

Chapter 2: Literature Review

2.1 Introduction

The progression of ill-health, end of life and subsequent post-death grief may be complicated, yet will pass through comparatively discrete chronological stages (Howarth, 2007a; Walter, 2017). As such, the exploration and structure of this literature review will be chronological *dying, death and bereavement*. The literature in each of these areas is diverse and spans well beyond the scope of sociology. Where key, the perspectives of other disciplines will be discussed, such as psychology, religion, biology and medicine. A sociological perspective has sometimes come later to critique the dominant views, and as such, it will be essential to understand what the basis for that critique is. In doing so, the exploration of the literature will also seek to outline the dearth of understanding of the lived experience at end-of-life and into subsequent bereavement.

Inequality is a dominant feature of contemporary Western society (Wilkinson and Pickett, 2010; Dorling, 2015). This inequality can be evidenced along the life-course, and into ill-health and mortality rates. Structural differences are often overlooked due to neoliberal rhetoric that promotes reduced state intervention, and increased self-management (Ayo, 2012; Peacock, Bissell and Owen, 2014b; Sturgeon, 2014). When individuals become unwell, it can be challenging to access healthcare legitimately and efficiently, due to blame being attributed to perceived individual failings. What affects this can have on the range of experiences of end-of-life and bereavement have often been overlooked.

While often not at the forefront of the sociology of death, dying and bereavement, there are notable examples where social class has been referenced and observed as being indicative of differences in receipt of treatment, the effect on identity, and interaction with healthcare professionals. There have been many calls for further research in this area, most notably by (Howarth, 2007b). The imperative to do so is to simultaneously:

- Disrupt the assumption of end-of-life as being the same for all

- To challenge the notion that difference in experience is simply that: difference

In doing so, this makes a bolder, political claim that it is structural inequality that impacts on the quality of care, the management of death, the response from the family, and the ability to make sense in bereavement.

This literature review will seek to explore the diverse study of and literature on the sociology of death, dying and bereavement. Following this, pronounced and entrenched health and mortality inequalities will be outlined and how they relate to different death, dying and bereavement experiences for different persons. I will demonstrate that these differences cannot simply be explained as social differences but that a closer look at these social divisions requires a focus on the important, yet highly contested area of social class. I will describe this concept in more detail and will explore how some research has observed that social class appears to create or led to a demonstrable difference in terms of dying and death.

This literature review attempts to bring together what have previously been discrete bodies of academic study. Every effort will be made to describe the rationale for the attention paid to it, and aim for the discussion to allow for the identification of gaps in our understanding, and thus, be clear where this research aims to redress this dearth in attention and knowledge.

2.2 Situating Dying, Death, Bereavement and the Role of the Carer

It is crucial to note the omnipresence of death (Becker, 1973; Hegel, 1977; Van Brussel and Carpentier, 2010; Holmberg, Jonsson and Palm, 2019). It can occur at any point of the life-course; young, old, suddenly, inadvertently, prolonged, elected. Death and its avoidance feeds some of the most primal responses to a perceived threat (fight or flight), or to prolong the species (mating ritual). Given the ubiquity and universal presence of mortality, it is understandable that it is a focus and motivation for a great deal of interest.

Within academia dying, death and bereavement is the focus of a multi-disciplinary arena. Death studies (also referred to as thanatology) is made up

of biology, medicine, anthropology, history, literature, psychology, sociology, archaeology (Hockey, Komaromy and Woodthorpe, 2010). Whilst this is not an exclusive list, it indicates the range of approaches that might be adopted to understand this inevitable phenomenon.

Sociology is oriented to understand the social world in which individuals and communities exist. The life-course of the human condition is one which provides discrete subject areas within sociology, given these can present with very different issues and experiences at different stages (Clark, 1993; Howarth, 2007a). To overlook this essential aspect of the human condition is to ignore one of the universal phenomena (Paradis, 1988). While shared, it is not the case that the experience is universally the same. This work is concerned with the end-of-life and how this aspect of the life-course affects those whom are carers and are then subsequently bereaved by the death of the person whom they care for and the difference of experience they have.

2.2.1 Sociological Perspective of Dying, Death and Bereavement

There have been numerous calls for dying, death and bereavement to be more central within sociology (Walter, 1992; Stanley and Wise, 2011; Thompson *et al.*, 2016). Within the social sciences examination and understanding of end-of-life and bereavement have often been dominated by psychology and medicine. While this has informed many areas, such as grief theory, how to break bad news for medics, and numerous clinical interventions and healthcare improvements, it can often be overly focused on the individual (Woodthorpe and Rumble, 2016). Whether that is the dying individual or bereaved individual, the focus is narrow, and it is pertinent to highlight “dying, death, and bereavement do not occur in a social vacuum” (Thompson *et al.*, 2016, p. 3). A great deal of work within the field of sociology has attempted to overcome this individualised and atomised view, by placing it in a wider relational and societal context.

Residing within the field of medical sociology, the sociology of death, dying and bereavement has focused on the area of the life-course which is sometimes avoided by wider society, or can make for uncomfortable consideration (Broom, 2015). However, it is something that nearly all of us

will have to attend in some capacity in our lives. Given the biological and emotional impact of death, one can appreciate how medicine and psychology dominate in professionalising, intellectualising and bureaucratising this field. However, it is vitally important that social science scrutinise this area, as failure to place these phenomena in a broader social context can be reductive, pathologising and lead to ill-informed assumptions (Howarth, 2007b; Thompson *et al.*, 2016).

Sociology views death and dying as a social issue, encompassing a multitude of rituals and cultural practices both historically and in the present (Field, Hockey and Small, 1997; Howarth, 2007a). As with any discipline, there are differences of opinion, and the scope of the subject areas is vast. From media portrayal of dying, death and grief (Raisborough, Frith and Klein, 2013), to the politics of euthanasia (Clark, 2002; Banerjee, 2008), and from the secularisation of funeral ritual (Walter, 2012), to the medicalisation and professionalisation, and subsequent demedicalisation, of death and grief (Lowenberg and Davis, 1994), there is a great deal of subject matter and important research being undertaken in this area. The effect of mortality on identity is an area which can vary depending on numerous factors, such as gender, ethnicity and, arguably, social class.

2.2.1.1 Medicalisation of Dying and Death

Kellehear (2007) outlines how historically in agricultural societies the relatively flat social hierarchy and close-knit, small populations meant individuals were more accustomed to death, which was seen as natural. As societies became more urban, complex and socially stratified, a professional elite emerged which was divorced from the realities of death in the community and family setting. This led to anxiety and a need for professional services to mediate this aspect of the life-course. While historically the specialisation of care for the sick has conveyed benefits to society in terms of increased life expectancy, there are concerns that death and dying are becoming invisible and removed from the community (Walter, 2010; Williams, Woodby and Drentea, 2010).

Improvements in biomedicine have led in recent decades to an increase in life expectancy in much of the Western world (Wilkinson, 1994; Cohen and Deliens, 2012). The treatment of disease and illness has conferred status, authority and power to the medical professionals, and as such death is now viewed as a medicalised stage of the life-course. Nearly all healthcare professionals are trained to treat patients in a manner that is curative and will prolong life (Lupton, 2006). While each of us will die, the cause can be highly varied. Different illnesses, diseases and conditions impact upon the patient in unpredictable and varied ways, which can make giving an accurate prognosis and projection of death very challenging and imprecise. Given the focus on longevity and wellness, there is reluctance on the part of medicine, patients, and wider society, to fully consider the dying process (Thompson *et al.*, 2016).

The delaying of death is also termed as 'death denial' by Kellehear (1984) and is linked to the shame and fear that dying evokes (Ariès, 1974). There have been campaigns, such as Dying Matters (<https://www.dyingmatters.org/>) and the proliferation of Death Cafes (<https://deathcafe.com/>), to raise awareness and increase the rates of individuals and their families discussing, planning and stating their care and memorial preferences for their death. It should be warned, however, that it is not necessarily positive for all and those who have had traumatic experiences with death (war veterans) should not be criticised for not engaging (Walter, 2017).

The suggestion that death is taboo (Willmott, 2000) has been critiqued by highlighting how in the media, from news to television soap dramas, death features readily and frequently (Woodthorpe, 2010). Furthermore, the growth of the hospice movement and palliative care, and additionally of counselling and bereavement services suggest that the framing of society as circumspect, cautious and death-denying, has been over-stated (Lee, 2008). It is argued that dying and death have been reconfigured and that new cultural expressions are emerging. However, Broom (2015) urges us not to overlook that within these changing responses to dying and death, structural issues and problems still persist, and new ones may emerge.

The practices which surround death as a life event have become institutionalised and primarily controlled by the medical profession (Banerjee, 2008). Illich (1975) states that a terminal diagnosis can have the profound effect of simultaneously placing the individual in a “borderland”, and also highlighting the eventual futility of medical intervention. He notes as the patient is now faced with their own mortality “the escalation of terminal treatments removes from the physician all need to prove the technical effectiveness of those resources he commands” (p. 107).

2.2.1.2 A Good Death: Hospice Care

The management and experience of dying have led increasingly to the desire for ‘the good death’ (McNamara, Waddell and Colvin, 1995). A ‘good death’ is considered one in which the individual has both some degree of awareness of the prognosis and control of how and where they are treated (McNamara, 2001; Howarth, 2007a). However, this does not necessarily constitute a good death for all. While there is some evidence to suggest that those from traditionally working-class backgrounds have less awareness and control (Seale, 1998), there has been little research to understand why this is the case or the impact this has on those affected.

The main driver attempting to improve the experience of care and symptom management at end-of-life in the UK has been through the adoption of the Gold Standards Framework (GSF). Originally developed in 2000 and trialled in Yorkshire (National Gold Standards Framework Centre, 2015a) it aims to enhance the coordination and quality of care for those receiving palliative care and reduce hospital admissions. Evaluations of the GSF have noted uptake of particular aspects of the protocols and guidance, but there is little to determine if this has improved patient outcomes and evidence to suggest that adherence is highly variable from setting to setting (Walshe *et al.*, 2008; Kinley *et al.*, 2014).

Palliative care and the hospice movement signify, to some extent, acceptance within the field of medicine of death, and the need to provide appropriate and tailored support. It previously had been suggested that there was relatively little sociological work on the hospice (Paradis, 1988). Lawton

(2000) undertook what has gone on to become a classic ethnographic study in a UK based hospice. She noted some profound aspects of the process of dying for individuals and the management of these individuals by the palliative care process. Self-identity, as she sees it, is contingent upon the functionality of the body. When this fails, there may not always be time or the will to reconfigure oneself in the new circumstances, as the 'unbounded body' (severely debilitating symptoms) can remove much of the individuals' characteristics (ibid). Hospices focus is on the management of the physical symptoms and effects of cancer.

Hospices are ill-equipped to deal with the needs of every individual, and at some points, the lines of choice and dignity are not always clear. While efforts may be made to attend to and manage the physical symptoms displayed by individual patients, this is done so within an organisational structure that remains concerned with operating an efficient and amicable environment for the majority of its patients, their family and the staff. This highlights how a palliative care provider that aims to attend to the dying with high levels of interaction and symptom management may still struggle to aid the transition, emotional work and life-course disruption that individuals have in facing their own mortality (Exley and Letherby, 2001).

There have been attempts to account for the difference in the hospice setting with the creation of a 'factfile' (Gunaratnam, 1997) in order that hospice staff have a reference that can guide their behaviour and actions around different ethnicities, faiths and cultures. By and large, this extends only to ethnic variations.

Due to a call to consider it (Field, Hockey and Small, 1997), there has been a focus on how the social divisions of gender and ethnicity manifest at end-of-life and in the experience of grief. Interestingly observational ethnography in a hospice suggests that gender becomes less of a defining characteristic of the dying the closer they are to death (Lawton, 2000).

2.2.1.3 Bereavement: From Stage Approaches to Continuing Bonds

In the period after the death of a close family member or friend, there is a period, which is not necessarily immediate or time-limited, of accompanying

upset and distress, and adjustment to ones altered circumstances without the deceased. This is commonly known as a period of bereavement or grief. As Lloyd (2018) states:

Death is a natural part of the cycle of life. Grief is therefore the normal response to the loss of a loved one. (p. 15)

There are socio-historic and cultural (including gender and ethnic) variations to bereavement. It is now understood that bereavement can be complicated and/or prolonged, dependent on personal and social circumstances (Parkes, 2008). Much of modern social expectations of bereavement have historical routes in religion (Walter, 2012) or psychology (Harris, 2010; Pearce, 2019).

The foundations of psychology and bereavement arise from the understanding that death leads to the loss of a social bond. This loss is felt as being more individually isolating than in pre-modern times due to larger populations. Whereas previously in small and tighter running communities, the loss of a person would see the loss of their social and communal role to the broader populous (Mellor and Shilling, 1993). The degree of attachment formed, and the style of attachment will be indicative of the severity of the loss (Bowlby, 1980). A formative essay in theorising bereavement was *Mourning and Melancholia* by Freud (1916). He posited that grief has to be processed and worked through in order that the bereaved can then detach themselves and move on with their lives (Mallon, 2008). However, critics have suggested that even Freud himself was unable to achieve the posited detachment in his own life, as he grieved for the loss of his daughter for many decades (Lloyd, 2018).

The work of Kubler-Ross in the 1960s has inspired some of the most influential public perceptions of grief and bereavement (Lloyd, 2018). Adapted from her work, a five-stage approach to working through bereavement became prevalent. These stages are denial, anger, bargaining, depression and acceptance (Kübler-Ross, 1969). With what has popularly thought to be the “desired outcome” (Samerel, 1995), acceptance was interpreted to suggest that being able to accept the loss and move on was the signifier that grief had been processed and was now over. While it has

been noted that Kubler-Ross did not suggest that this is a linear or prescriptive set of stages (Valentine, 2006) this has not yet filtered through to wider society and other models or theories of bereavement “seem to be overlooked” (Lloyd, 2018, p. 34). What the consequences of this gap in understanding and societal norms are is unknown and under-researched.

In recent decades there has been a shift from stage-based grief models to empirically informed theories of bereavement. Theories of grief have long been rooted in psychological approaches. Epistemologically, much of the work to understand the psychology of an individual has been established in quantitative work that aims to satisfy positivist ontology by testing hypotheses and uncovering the processes by which the mind works through grief. One such theory that moves away from this is that of continuing bonds (Klass, Silverman and Nickman, 1996), which has challenged previous work that implies a goal of “acceptance” of loss. In conducting and reflecting on qualitative work, it was noted that dominant beliefs on bereavement did not reflect the experiences of participants in their research. In the book *Continuing Bonds: New Understandings of Grief* (1996), Klass, Silverman and Nickman state:

The resolution of grief involves continuing bonds that survivors maintain with the deceased and that these continuing bonds can be a healthy part of the survivor’s ongoing life. (p. 22)

This work suggests that it is reasonable and healthy to continue to have a relationship with the deceased. By this, it can mean visiting a grave, keeping ashes on display, and talking to the deceased beyond their death (Root and Exline, 2014; Lloyd, 2018). It acknowledges that a secure attachment which is subsequently lost will have repercussions for time to come. It promotes a continuation of remembrance, through acts of commemoration or frequent reflecting on memories with the deceased, to acknowledge the absence while also adapting to new life circumstances. While from the modern sociological perspective this may seem self-evident, the departure from psychological models of grief was radical.

While the recent developments in the understanding of bereavement have supported and promoted a broader and more flexible approach to grief, it still appears to be the case that lay beliefs orient to a stage-based approach being more normative (Pearce, 2019). This may be due to the historical legacy of these approaches and their popularity in the media (Lloyd, 2018). However, the consequences of this prevailing discourse on processing grief, and the impact on the individual, are not fully understood. Klass, Silverman and Nickman (1996) noted that some people might be put off talking therapies to aid their bereavement for fear that they may be instructed to “forget about” the deceased.

Concerns of research participants (Klass *et al.*, 2000) about the potential prescriptive guidance of talking therapies would indicate two pertinent things: firstly, that the developments in understanding and theorising of healthy bereavement, which now acknowledge an ongoing relationship with the deceased, have not left the confines of academic discussion and filtered down to wider society. Secondly, that if the talking therapy or therapist does not themselves recognise a wide range of bereavement responses, that a grieving person entering a therapeutic relationship may be exposed to more harm than good if their behaviour is pathologised.

2.2.2 Differences in Death, Bereavements and Grief from a Sociological Perspective

It should be noted that sociologists have been at the forefront of critiquing and considering the work surrounding grief and bereavement. The threat of medicalisation is real. Pearce (2018) describes the reaction to the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) in 2013, when it was suggested that if bereaved people showed depression-like symptoms for more than two weeks, they could be diagnosed as having a major depressive disorder, which sparked a widespread backlash:

The substantial criticism that arose from these changes centred on an objection to what was seen to be an increased ‘medicalising’ of grief. (p. 8)

It is argued by Pearce (2018) that the boundaries between the private and public realms of grief are less clear cut than academics previously suggested, with regards to death being a 'taboo' subject (Valentine, 2006). Rather than coming to bereavement ill-equipped to cope due to the sequestration of death, it is argued that there is evidence of people finding and making meaning and managing their grief in new ways, such as online in discussion forums (Pearce, 2018). As noted above by Lloyd (2018) that bereavement is seen to be and remains a rational and reasonable response to death should be as expected as death itself.

Where grief is 'complicated', 'prolonged' or otherwise causing distress that leads to a lack of ability to function day-to-day, there are treatments in terms of medication, and talking therapies available. Accessing treatment requires uptake the bereaved to be forthcoming. This can be difficult, or a non-option, for some:

[...] Shame is a key psychosocial mechanism in this process, which results from and can lead to a feeling of being negatively judged as inadequate and disempowered.

(Holman, 2014, p. 542)

2.2.2.1 Funeral Practices and Memorialisation

In the time immediately after the death, the family will be expected to make arrangements for a funeral. The funeral serves multiple functions such as allowing space to replicate social norms (Kearl, 1989), the giving space for an outlet of grief and emotion and therefore aid the bereavement process (Howarth, 2007a). In order to arrange a funeral, there are administrative and social expectations. A funeral director may be instructed to manage some or all of the arrangements; this can be a testing time for families and made worse by poverty (as will be discussed further later).

There has been evidence to suggest that gender, ethnicity and culture affect bereavement and shape the response of individuals, families and communities to death, funeral practice and the period of grief that follows (Valentine, 2006). Anthropological studies have documented the wide-ranging funeral practices across the world (Bailey and Walter, 2016).

However, despite some allusion to it where notable cases of the decoration of graves make local headlines (Johnson, 2016), or when a working-class celebrity dies (Raisborough, Frith and Klein, 2013) there has been little academic attention paid to working-class communities in bereavement studies.

The attention given by academia, particularly literary studies, to eulogies, grief accounts, memoirs and their legacy to those who are bereaved is interesting (Neimeyer, Klass and Dennis, 2014). Arguably this form of creative expression is not available to all in society. The time, capacity and resource to communicate the bereavement and loss are not equitably distributed. Not to mention access to an interested publisher. If we understand this to be a phenomenon that will be mostly characteristic of a more affluent and upward socially networked section of society, what kinds of ritual and memorialisation are those from disadvantaged or working-class communities partaking in? The evidence is scant.

While there is a description in the academic literature of a proliferation of new and varied ways to memorialise the death of a loved one, there is little to suggest who and under what circumstances these are taken up. Beyond benches, flowers and trees, Lloyd (2018) describes:

Imaginative ways have been developed to memorialise ashes: pressing them into vinyl records, creating jewellery with ashes, adding them to ink prior to tattooing, adding them to paint before a portrait of the deceased has been created. There is even a company that will create fireworks with the ashes of loved ones. (p. 40)

Ritual practices may be inspired by other cultural approaches to memorialisation. For instance, tattooing originally was a practice in Polynesia (Te Awekotuku, 1997) that has since been adopted in the West (Walter, 2012). Nevertheless, there is much yet to be understood with regards to memorialisation.

Whilst the range of cultural approaches to funeral practices and memorialisation may have been well documented historically, and globally,

what is less well understood is the experience of those family members that may have had a profound and intimate relationship with the deceased.

2.2.3 The Relational Experience of Carers and Their Families: A Hidden Population

Until the 2000s, the interest of the experience of informal carers was mostly psychological and psycho-oncological. However, sociological and feminist research has become more prevalent in recent years (Thomas, Morris and Harman, 2002). This may in part indicate a 'hidden' population, as the observation that many people do not always identify themselves as, or identify with the term, "carer" (Knowles *et al.*, 2016).

The dying process can be one that is highly individualised, not only by the person dying and their focus of their surrounding family but particularly by the interactions with and treatment by the medical profession. The focus may become very narrow in terms of symptom and pain management, dealing with identity issues and future trajectories and 'calendar construction' (Schou, 1992). The amidst of all the attention and attempts to reconcile oneself to the onset of end-of-life, it is often the case that focus is on the loss of normality (identity and bodily function) and adjusting to the limited time remaining (Lawton, 2000) . Often the experiences of those family members or friends closest to and providing care for the patient can be overlooked, but there is literature to suggest that this is an area of increasing importance.

As well as the day-to-day care of the sick person, numerous complicated factors can add further pressure to the situation for carers. These challenges can range from financial constraints to familial issues. Research undertaken by Moffatt, Noble and Exley (2010) highlighted how the financial complications that can arise as a result of a cancer diagnosis are further heightened by lack of awareness and knowledge of benefits entitlement. Carers may also face making decisions on behalf of the patient. This can be stressful and upsetting, yet lack of awareness and discussion about the advanced planning of care and wishes is still prevalent (Dickinson *et al.*, 2013).

Further, when managing and seeking access to appropriate support, lack of information about how to obtain support from relevant health organisations when providing care for someone who is terminally ill was found by McNamara and Rosenwax (2007) in Australia to lead to some carers to suffer a decline in their health, and/or to report that they felt unable to cope after the death. There is consistent evidence that carers find it challenging to find out what support they are entitled to, and there have been calls for organisations to reflect and adapt their outreach programmes according to the needs of the most vulnerable (Moriarty, Manthorpe and Cornes, 2015).

Taking on the responsibility of care can mean acting on behalf of the dying in a way that can appear detached. The body of the unwell when in crisis, is the site of absorption, be it of aid, intervention or technology. Lawton (2000) noted her experience of witnessing carers or family members speaking on behalf of the patient who was present as if the patient is not there. This was not challenged by the patient.

Both a carer and a prosthesis become merged with a patient's body, because what both have in common is that they constitute the source and/or means of that patient's bodily mobility. (p. 112)

The importance of shared decision making between healthcare professionals, patients and their carers has received more attention and increased efforts to address this relationship. Hubbard *et al.* (2010) evidenced how carers “act as both conduits for information and knowledge exchange and facilitators in the process of deliberation” (p. 2029). They assume responsibility for asking questions and processing complex information or prognoses throughout the trajectory of interaction in clinical settings.

It is clear that, in addition to the care work required by the family member or friend, there is also additional emotional and psychological work that has to be undertaken:

In doing this emotion work, carers, especially spousal carers, often symbolically shared in the illness and presented the

struggle with the cancer as a joint one. (Thomas, Morris and Harman, 2002, p. 542)

Emotion work of informal caregivers has come under closer scrutiny. A shift is suggested to move from focusing on “hope” or “inner strength”, to recast and encourage carers to orientate their conceptions of time and future trajectories differently, with a “live for the day” approach beneficial for some (Olson, 2011). While this may be the case for some, those from a working-class background who already value a “live for the day” approach could potentially find themselves in a difficult period of transition once their family member has deceased and they have to recapture their own identity and future trajectory.

The likelihood of provision of informal care from within the family is determined by social position, with those from disadvantaged or working-class communities more likely to take on the care for an unwell relative (Arber and Ginn, 1992). It is noted that this is often done in more challenging circumstances, in that they:

Face the greatest burden of providing care, while at the same time possessing fewer material, financial and cultural resources to ease their caring burden. (p. 631)

Differences in approach or activity with regards to the quantity and intensity of care work undertaken, may in part, be due to how the individual sees their relationship with them. For some, such as migrant carers, there is an idealised view that some persons are more appropriate for care roles (Weicht, 2010). This moralising discourse can be evident in the manner in which some carers narrate their orientation or involvement with informal caring (Pickard, 2010).

When the need comes for a family member who becomes sick or unwell to need additional support, it is often the family that will step in and aid them. While much research focuses on an individual or primary carer, often whole families have to adapt and use their network to provide assistance (Moen and DePasquale, 2017). However, there is evidence that those from lower socio-economic backgrounds are more likely to experience familial conflict in

the face of a crisis (Kramer *et al.*, 2010). Lack of support from family, and particularly from organisations that should provide supplemental support can lead to “poor end of life outcomes unless additional and/or alternative relations or networks of support are identified and resourced” (Lewis *et al.*, 2014, p. 7). There are calls for further research into the differences and effects of socio-economic and classed based experience of informal carers at the end-of-life (Thomas, Morris and Harman, 2002).

Familial issues can remain at the centre of focus post-death, particularly when it comes to dividing and divulging belongings and assets, and also when it comes to matters of inheritance. Finch and Mason (2000) note that inheritance is about actively making and doing kinship. While they found only a minority of instances of familial conflict related to inheritance, it was noted by one of their participants that it had the effect of having “caused quite a stir” and being “quite traumatic” (p. 84).

2.3 Power and Positionality: Inequality and Social Class in an Era of Neoliberalism

I have explored the research and literature on the sociology of death, dying and bereavement, and in a limited manner touched upon some of the areas of difference for those from disadvantaged communities and families. This section aims to describe in greater detail the prevalence and impact of inequality in contemporary UK society. In doing so, it will make the argument that inequality is indicative and informative of social positionality, and that within a socially hierarchical this means that social class is indicative of the relationship with and to power. By contextualising the neoliberal ideological structure in which organisations reside and individuals are faced with navigating it, will allow for the final section of this chapter to assess how far the current understanding of death, dying, bereavement and their intersection with social class go.

Western societies in the 21st century are very much an example of technological revolution and of an acceleration in improving living standards. Nevertheless, inequality exists and has existed across many cultures and

throughout history. There has been an unabating widening of inequality, despite the progression made with regards to living standards (Wilkinson and Pickett, 2010). Individuals within a society are often competing for scarce resources and will do so with a variety of constraining or enabling factors while doing so. This effect is to stratify those within society.

In their seminal work, *The Spirit Level*, Wilkinson and Pickett's evidence using inter-national and intra-national statistical data that it is structural inequality, and not merely poverty, that has a deleterious consequence on a range of social issues, such as health, crime and mental illness. Their work highlights the strong correlation between the level of inequality and the severity of the social problems faced by those at the bottom. Described as "divisive and socially corrosive" (*ibid*), inequality undermines trust, a sense of community, and can contribute to physical and mental ill-health.

However, inequality is not inevitable. Particularly the levels of inequality that have been documented in recent decades, it is argued, is a choice and by-product of wealth and power being concentrated in the hands of few. The reason why inequality is important is that it is avoidable and yet can have profound consequences, yet oppression is not inevitable (Harris, 2010). Dorling (2015) suggests that we must see the notions of choice and agency as a myth as they do not apply to all in the same way as will be outlined below. In 2008, the World Health Organisation stated clearly: "Social justice is a matter of life and death" (Commission on the Social Determinants of Health, 2008). It is therefore vital to place into context the structural issues and limitations that many are facing, and note that if the political will was strong enough, it could be addressed.

2.3.1 Inequalities in Patient-Doctor Interactions

One way in which inequalities are expressed in the healthcare system is evident in the interactions between patients and professionals. Doctor-patient interactions are often the vehicle by which healthcare can intervene and prevent, cure, or alleviate the (potential) suffering of an individual. However, these interactions have been shown to vary and thus, the quality of care can differ from one social group to another (Lupton, 1997a; Morgan, 2018). The

result of the variability of these interactions can have lasting effects on individuals and also, more widely, the ability of the healthcare system to challenge enduring inequalities in the health outcomes for differing social groups (Verlinde *et al.*, 2012).

Further to this, at end-of-life open and transparent discussions with patients and their carers/families are vital to ensuring that palliative care can be undertaken at the appropriate time, that the patient and carer(s) understand the situation, allowing any decision-making required to be timely, appropriate and reassuring.

The dynamic of the doctor-patient relationship has been of sociological interest since the 1950s when Parsons (1951) introduced the notion of the 'sick role' and the relative power of the medical profession to give or deny legitimacy to the claim of ill-health. The label of illness or the sick role allowed for exemption from normal duties and responsibilities, and also to claims for additional support. These allowances are only legitimised with the concurrence of an authoritative healthcare professional. In part, this theorising led to empirical work to understand the relationship and interaction between doctors and their patients.

Historically doctors and the medical profession have long been revered, and the power of medicalisation to decree ill and healthy individuals has increased over that time. The relationship between doctors and their patients is of interest due to the wide range of outcomes they can produce (Lupton, 2006). Prevailing health inequalities indicate that the social grouping which one belongs to can be suggestive of the health status and outcome (Wilkinson and Pickett, 2010; Dorling, 2015). Pilnick and Dingwall (2011) note that despite the deliberate attempts to incite cultural change in recent decades for a more patient-centred approach, doctor-patient asymmetry continued to be a problem into the 21st century.

The evidence suggests that minority social groups and those associated with lower status are most at risk from receiving comparatively more inferior doctor-patient interactions (Boulton *et al.*, 1986; Morgan, 2018). Much of the literature amalgamates both ethnic minority groups and low social-economic

status (SES) groups. However, there is evidence to suggest that those from low SES backgrounds are viewed more negatively and receive poorer care as a result of doctor-patient interactions (Satel and Klick, 2006). One explanation for this discrepancy is that patients from lower SES are more likely to be perceived as having negative personal traits and a lower level of intelligence.

[...] Lower SES patients were rated as less likely to be compliant with cardiac rehabilitation, less likely to desire a physically active lifestyle, less likely to have significant career demands, less likely to have responsibility for a care of a family member and more likely to be judged to be at risk for inadequate social support. (Van Ryn and Burke, 2000, p. 821)

These suggested presumptions about patients from disadvantaged or lower SES backgrounds are highly negative. Research suggests that it is not only the perception doctors have of their patients' status that is influential, but also their conduct in the medical interactions they have with them (Boulton, 1986). Patients from lower SES less likely to ask questions of their doctors when in consultation with them:

[...] Which may both result from and reinforce physician judgements regarding their intelligence and rationality; they may ask less questions because physician affect and behaviour toward them is discouraging (perhaps unintentionally), and physicians may develop or reinforce beliefs about patients' cognitive ability or information needs based on their question-asking behaviour. (Van Ryn and Burke, 2000, pg. 823-4)

Doctors' perceptions, such as these can lead patients to receive a differing level of care that they perceive differently. In turn, patients may experience lower levels of satisfaction in their care, trust in the physician and an increase in the level of stress the encounter induces (Boulton *et al.*, 1986; Lupton, 1997b).

Willems *et al.* (2005) noted that social class was a significant indicator in the style of the medical encounter, and their work confirmed previous suggestions that doctors act differently when treating patients from lower SES backgrounds. Their research also indicated that patients' satisfaction is strongly correlated to their subsequent adherence (Morgan, 2018). With doctors less likely to adopt a participatory approach, those from working-class backgrounds are more likely to have didactic interactions that may leave the individual feeling unsupported. The social and cultural difference between doctor and patient can provide barriers to providing and receiving adequate care (Schouten and Meeuwesen, 2006). The social distance between doctor and patient, whether based upon assumptions or real, can have a stultifying effect on patient outcomes (Boulton *et al.*, 1986; van Ryn and Burke, 2000; Willems *et al.*, 2005; Chang, Dubbin and Shim, 2016; Morgan, 2018).

Socio-demographic characteristics may be associated with an actual difference and it may be the case that these differences are based on genuinely observed individual differences and useful for the interaction (Lupton, 1997a). Alternatively, epidemiologic evidence may be incorporated into doctors' beliefs, even where disconfirming individuals are presented (Van Ryn and Burke, 2000). Given the context of their work, they may be at increased likeliness of falling back on stereotypes of patient characteristics (Verlinde *et al.*, 2012). This may be due to time pressure, brief encounters and complex cases. However, this risks stigmatising and discrimination (Chang, Dubbin and Shim, 2016), and the resulting consequences show enduring health inequalities and a distinctively inferior level of interaction and care from physicians (Morgan, 2018).

Whilst some sociological analysis will highlight the negative consequences of the uneven power relationship, many lay persons will be comforted by the expertise and defer to the perceived wisdom of their doctor.

Any response to the doctors assessment that challenges this asymmetry inescapably undermines the patient's grounds for

seeking professional medical help in the first place. (Pilnick and Dingwall, 2011, pg. 1380)

It is true to note that there is an inexorable power dynamic. However, the pertaining health inequalities for certain social groups that are sustained for the medical profession are more worrisome and cannot be explained away by this. The position in which lower SES patients find themselves has been described as creating a "vicious circle" or double bind (Willems *et al.*, 2005) by both the tendency to present more passively during medical encounters and due to the perceptions that doctors may have that they are less intelligent or are not interested in their health. The variability of these encounters may do little to challenge healthcare professionals' assumptions, and the paternal interaction may reinforce the acquiescent and docile behaviour presented (Chang, Dubbin and Shim, 2016).

Despite efforts to redress the imbalance of power over recent decades, analysis shows that there has been little change, and where patient-centredness has been advocated it has not always necessarily led to an improvement in health outcomes (Pilnick and Dingwall, 2011; Chang, Dubbin and Shim, 2016; Morgan, 2018). To the NHS paternalism is fundamental, given that medical treatment has the potential to harm as well as heal (Peck and Conner, 2011). A prescribing doctor is accountable for these decisions, and it is right that the balance of power lies with the medical staff. However, Pilnick and Dingwall maintain that this differs from consultations taking an authoritarian approach - "authority can and should be exercised in a civil fashion" (pg. 1379).

While there is a body of evidence that points to lower SES being a factor in differing treatment from healthcare professionals, there is also evidence to suggest that in some cases, other factors may also contribute. For example, Hall *et al.* (1993) found that patients who were sicker tended to be less liked by doctors. Similarly, Sudnow (1967) observed that patients who were considered deviant received poorer follow-up care. The potentially stigmatising perceptions of patients may be bound up in a complex multitude of associations that are not only class-based but also include perceptions

related to gender, ethnicity, age, educational attainment, etc (Verlinde *et al.*, 2012; Chang, Dubbin and Shim, 2016). The intersectional nature of these attributes requires additional scrutiny. However, class-based inequalities remain difficult to overcome despite interventions to do so (Boulton *et al.*, 1986; Pilnick and Dingwall, 2011; Morgan, 2018).

Continuing health inequalities are both difficult to challenge in practice, but also can be subject to radically differing explanations. These explanations can often be part of broader political rhetoric which may focus attention or attribute blame for these inequalities to different parties. Those from working class communities may find that they are blamed for relative ill-health which can be difficult for those with lesser power and status to challenge (Bradby *et al.*, 2020). These neoliberal explanations may deflect attention from lack of training or resources within the health system and allow the health inequalities to become more acute.

2.3.2 Drivers of Inequalities: Economic, Geographic and Health

Inequality is a prominent feature in the UK and effects many aspects of social phenomena at all levels; micro (individuals, identities), meso (organisations, practice), macro (government, discourses) (Halfmann, 2011). Evidence continues to highlight that inequality is entrenched and worse than previously estimated (Department for Health, 2020). The following section aims to briefly review the evidence that highlights the effects of inequality. This will allow for an argument to make that social difference is not just that, *difference*, but instead, it is clear that it is a stratifying force that confers position and power. Therefore, we cannot understand the experiences of those disadvantaged by inequality, without considering their relation to social class.

Occupation, income and wealth are important indicators of inequality as so many other measures of inequality, such as educational attainment, rates of mortality, correlate with the proportion of financial resources held and demonstrate a clear social gradient (Marmot and Bell, 2012). Statistics indicate that the wealthiest 10% of households have over 850 times the wealth of the least wealthy 10% (Collinson, 2012).

Growing income and wealth inequality is recognised as the greatest social threat of our times. (Dorling, 2019, p. 1)

The increased scrutiny of the distribution of income and wealth has noted that vast sums of wealth are concentrated in the hands of a few. As Wilkinson and Pickett (2010) suggest that it is not simply poverty or lack of wealth, but the severity of the degree of inequality between those at the top and the bottom, within a society that correlates with an increase in the severity of social problems. A clustering effect means that disadvantage affects some more, and more frequently, than others:

Disadvantage has many forms and may be absolute or relative. It can include having few family assets, having a poor education during adolescence, having insecure employment, becoming stuck in a hazardous or dead-end job, living in poor housing, trying to bring up a family in difficult circumstances and living on an inadequate retirement pension. (Wilkinson and Marmot, 2003, p. 10)

2.3.2.1 Place Matters

Where an individual lives is also indicative of health inequality. Stockton-on-Tees (one of the boroughs included in this research, and also where I grew up and live) has the highest gap in life expectancy in England within its wards at over 17 years for men, and 11.5 for women (Bambra, 2016). In an influential report, Whitehead (2007) stated that amongst several factors:

[...] The main cause of the observed health inequalities within and between North and South are: Differences in poverty, power and resources needed for health. (p. 8)

As Bambra (2016) notes these differences are often reported in popular media as being related to 'health behaviours' (such as smoking and obesity) however evidence suggests that even taking those factors into account what is more influential are material, psychosocial and environmental factors.

2.3.2.2 Economic Pressure and Mental Health

Clearly continued health inequalities are linked to structural issues. It is significant to highlight with regards to health, these disparities have been explained to be caused by slower economic development. When compared overall to the South, the consequence is “higher unemployment, lower incomes, adverse working conditions, poorer housing, and higher unsecured debts” (Whitehead, 2007).

Taking seriously the World Health Organisation (WHO) definition of health which notes that it is not merely the “absence of disease”, but also extends to mental and social well-being, it is crucial to consider the inequalities evident in mental health (World Health Organisation, 2020). Significant scrutiny has been paid to mental health provision in the UK in recent years and mental health disparities are also consistent with societal inequality (Wilkinson and Pickett, 2010). However, even historically since 1855, there have been reports that there is a high prevalence of psychiatric disorder amongst those who are of low socio-economic status or social class (Angermeyer and Klusmann, 1987).

Bambra (2016) explains the discrepancies in mental health for different social groups using some key examples:

[...] In the case of psychotic disorders, the prevalence is among the lowest quintile of household income is nine times higher than in the highest. This is not just a result of downward social mobility (as it is harder to find and maintain employment when suffering from a severe mental illness). The social gradient is also evident for common mental health problems, with a two-fold variation between the highest and lowest quintiles. (p. 101)

The reported rates of suicidal thoughts have increased between 2000 and 2007, with “a further increase to be anticipated” (Dorling, 2015). It has also been the case that these inequalities are geographically distinct, with higher rates of suicide recorded in the North than in the South (Bambra, 2016).

Additionally, increasing mental health problems are thought to be contributing to physical ill-health. The notion that a despairing, anxious, isolated or depressed individual is more likely to also, or as a consequence, become physically unwell is increasingly suspected to be linked to inequality (Dorling, 2015). The stress of suffering multiple forms of disadvantage, inequality and social troubles cause detrimental 'psychosocial' effects (Wilkinson and Pickett, 2012), which have a compounding effect and make achieving positive change difficult for individuals, families and their communities.

All of the evidence regarding inequality suggests that the best way to tackle disadvantage and improve the lives of all within society is to work towards creating a more equal society. This would improve financial stability, health and wellbeing, rates of crime, educational attainment and positively progress communities (Bambra, 2016; Wilkinson and Pickett, 2010).

2.4 Social Difference of Socio-economic Status and Social Class

The previous section discussed persistent experiences of inequalities in a stratified society. Nevertheless, the consequences of a socially stratified society are not always measurable by quantifying wealth, educational attainment and tracking incidence of morbidity and mortality. Therefore, it is important to consider 'social class' as a positional and divisive explanation of social stratification and hierarchy. Yet first, I shall discuss why social class is essential to our understanding, and outline the calls of some academics to reject a framing of inequality as 'social difference'.

2.4.1 Why Is It Not Social Difference?

In attempting to understand the absence or reluctance of the sociology of death, dying and bereavement to consider social class, it is interesting that there has been widely acknowledged and studied variations at the end of life with regards to other social difference. 'Social difference' is a term that is frequently employed in attempting to explore and describe variation at end-of-life and in bereavement, and can be seen to encompass numerous differences: gender, ethnicity, geography, inequality, poverty, disability, mental health, homeless, travellers, substance misusers, prisoners,

LGBTQI+, and asylum seekers and refugees (Small, 1997; Oliviere, Monroe and Payne, 2011).

It has been evidenced that inequality is entrenched. Despite this, it would appear that the language and terminology around it changes in an effort to distance. Scambler (2018) notes that terms like 'inequality' or 'class' were supplemented with terms like 'health disparities' in North America, and 'health variations'.

Attempts to address and lessen, health-related inequalities in particular, have often struggled to ameliorate the problems. These initiatives have happened at a local, national and international level. The struggle is likely to continue, as Scambler (2018b) points out:

It seems likely that the enduring contradictions within capitalism – social and private appropriation, the strategic rationality of the corporation and the economic 'anarchy' of the wider society, the polarizations of wealth and poverty, the privileging of profit over need – will continue to frustrate the necessary reforms. (p. 155)

By not recognising these forces as ultimately constraining and stultifying any real progress to reduce inequality, we fail to acknowledge the power of social structures, such as social class, as a determining factor. Scambler notes that organisations such as the World Health Organisation (WHO) have tremendous strategic power to influence governance and policy, yet by failing to acknowledge health inequalities are related to “the contradictions of capitalism, thereby denying them an explanatory role” (*ibid*, p. 155).

In an international comparative study of income inequality, Coburn (2004) concluded: “that economic wealth is not even a necessary condition for health” (p. 53). This is highlighted by the relative health parity achieved by nations that have demonstrably more equitable income and wealth distribution and substantial welfare regimes. There is an explicit link between the ideological pursuit of a country and their health inequalities:

What is clear from the data presented is that countries pursuing neo-liberal policies display far greater social inequalities and show more people in absolute or relative poverty than do more social democratic nations – an indictment in itself. (ibid, p. 54)

As well as considering the effects of unequal distribution of power and resource, Ridgeway (2014) implores us also to consider how it is maintained by influencing and utilising cultural beliefs regarding status. These can be effected and mediated by ‘gateway interactions’:

There are interpersonal encounters that take place in organizations – such as educational, workplace, or health institutions – that mediate people’s access to the valued life outcomes by which we judge inequality, like good jobs, income, positions of power and health. [...] Class-based status beliefs are especially likely to become salient in gateway encounters when participants differ in class background, and the status biases about competence that they introduce have consequential material effects. (p. 10-11)

While there may not be societal (or academic) recognition of the terms working-class or middle-class in the way that people might have previously strongly identified with, it does not correlate that the power that lies behind socially stratifying mechanisms has waned. In fact, the evidence discussed throughout this chapter would suggest that it has intensified.

There are numerous reasons why there is a continued focus upon social inequalities that attempt to treat the causes as distinct and discrete from the outcomes. Firstly, research in the health sciences and particularly that of public health has a longstanding focus on ‘behavioural choices’ and belief (despite evidence against) that interventions to change the lifestyle choices of ‘unhealthy’ individuals will result in improved health outcomes (Williams, 2017). Secondly, as Garthwaite *et al.* (2016) note:

Researchers who are strongly committed to positivist approaches are unlikely, for example, to appreciate the benefits of ethnographic or co-produced research and may dismiss critical materialist work as being overtly ideological.

(p. 17)

Tracing back to the Enlightenment, much knowledge production has been thought to be of a higher standard or calibre if it is perceived to be 'objective'. While this is a vast and profoundly philosophical debate to touch upon lightly, it must be noted there are suspicions around work that for some, is deemed 'too political'. However, it would appear, as the evidence discussed suggests that the ideological pursuit of particular agendas by their very nature actively disadvantage some social groups at the expense of a few, which is an ideological and political issue.

Despite the vast amount of statistical and epidemiological evidence, the human consequences of continuing and widening inequality are not to be overlooked:

To be denied access to opportunity and a decent standard of living due to lack of resources is only one piece of the jigsaw. The others, including access to networks, social capital and the respect and dignity that accompany these, constitute an additional layer of barriers for poorer people. (O'Hara, 2020, p. 208)

The evidence and explanations provided are by no means an exhaustive list. It may be an uncomfortable and challenging argument to make that inequality is not 'just difference'. However, we must act, and in undertaking an action sociological approach, we must "hold our nerve and ground" when faced with denial and complicity (Scambler, 2019).

Many a lauded thinker has posited over death and mortality, and it appears to be a source of fascination when thought of in the theoretical or abstract. Nevertheless, it is an authentic and felt event. Here I shall discuss some of the observations made of death and dying in the body of sociology. In a

critique of Bauman's (1992) notion of the 'absolute and blind randomness' of death, Kellehear (2007) remarks:

[Death's] distribution draws a dark line between social position and death. Death and dying are not randomly distributed and never have been. Such comments about 'randomness' reflect anxiety about the vulnerability in a population with enough time and lifestyle comforts to theorise about it. (p. 183)

To what extent might Kellehear's observation explain the neglect of attention to working-class culture and experience in the sociology of dying?

Howarth (2007b) posits the question as to why, despite there being an interest in other forms of social distinction (e.g. gender, ethnicity), social class has remained largely ignored in death studies. Crompton and Scott (2005) suggest that the decline in interest may be due to the middle-class agendas of academics, and the way in which research is funded by groups with a particular focus. This is not to say that there have not been significant contributions to the debate around social class more generally within sociology over the past decade.

Additionally, there has been little interest in understanding the bereavement experience of those from working class communities:

It has long been known that perspectives of the social status (in general terms) of people who are dying may influence the social support those people are likely to receive from professional sources. However, there is little information available concerning possible relationships between the perceptions of the status of a bereaved person and the support they are likely to receive from informal sources. (Littlewood, 1992, p. 103)

2.4.2 Class as a Contested, But Pertinent Concept

Social class is a long-studied and debated concept that many of the big-name thinkers of the sociological canon have grappled with. The term 'class'

itself is contested, as I have described, and the attempts to theorise and operationalise it have varied hugely. I shall discuss some of the critical aspects to understand about social class while being mindful not to pigeonhole a bounded definition of who is/are not 'working-class'.

Capitalism, and the mode of capitalism, has a determining effect on the shape of social class. In order to maintain a power structure whereby the majority of society must work for their income by selling their labour, and a minority of society profit from that by extracting excess value, it is inherent that exploitation and subjugation occurs. These ideas, first postulated in this way by Karl Marx, set the tone for debate up to and including the present day, around the boundaries and abilities of this economic and materialist formulation of class relations to explain the world (Wright, 2015). For centuries this was debated, but the focus was often on the economic relations of social groups.

However, there was what became termed 'a crisis of class' in the 1980s and 1990s (W. Atkinson, 2015). Much attention had been paid to occupation and income as a means of determining social class. Economic capital is taken to describe the material assets that one has. This refers to the income, wealth or economic resources someone can draw upon (Jenkins, 1992). Due to the straightforward operationalisation and measurement of economic capital, much focus and attention have been given to understanding the effects of income and wealth, and the consequences of the unequal distribution of these resources (as has been described in previous sections). It is problematic to only understand class based only on economic determinism, due to the body of evidence that would suggest that there is more at play (Veenstra, 2007; Stephens, 2008; Savage *et al.*, 2015).

This concept did not seem to correlate easily with changing societal conditions. It was argued that in a more 'individualised' society (Giddens, 1990) the traditional notions of a socially stratified society did not reflect the changing landscape of positionality and cultural relations. One criticism of the narrow focus of economic determinants of class was that it:

Ultimately prioritised employment as the key axis of inequality, leading to the marginalisation of other axes of inequality such as gender, race, ethnicity and age, and that it relied on discredited, 'enlightenment' theoretical foundations.

(Devine and Savage, 2005, p. 1)

In a changing political climate, which saw the undertaking of a neoliberal political agenda under Margret Thatcher in the 1980s, resulting in mass de-industrialisation, and the repealing of the welfare state (Savage *et al.*, 2015; W. Atkinson, 2015).

As noted previously, there have been those that have argued that a neoliberal political agenda has also had consequences on social class. The evidence regarding inequality and health inequalities notes that there is a correlation of a steeper social gradient of inequality being evident in those countries that are guided by neoliberalism (Coburn, 2004). Neoliberalism is the ideological perspective that believes and seeks to suggest to citizens, that the market is the mechanism by which to fairly and equitably distribute scarce resources by virtue of competition (Harvey, 2005).

Regarded as a slippery concept (Peck, 2013), neoliberalism seeks the 'reformatting of social and political life in terms of its ideal competition within markets' (Dean, 2009, p. 52). Where efficiency and efficacy are applied to public services and institutions, such as the NHS, it places the need for accountability and reliability in order to assure that costs remain low (Brown and Baker, 2012). For the individual, there is an increasing expectation on maintaining one's health. Ill-health is viewed as a personal failure (Lupton, 2006). Ayo (2012) demonstrated how the rational argument of neoliberalism is effected through health:

1. *Minimum government intervention*: withdrawal of investment in the social of determinants health
2. *Market fundamentalism*: a market of expertise and lifestyle advice is created by reduced state intervention
3. *Risk management*: the potentiality of ill-health is framed around the risk of morbidity or mortality

4. *Individual responsibility*: a moral virtue alludes that individuals must do their civic duty by maintaining their own health through appropriate lifestyle choices
5. *Inequality as a consequence of choice*: any inequality is legitimised as a personal failure as responsibility is transferred from the state to the individual

This has direct consequences for those attempting to access support and help in times of crisis. Thompson (2016) notes the consequences:

Public and social services are: (i) reduced to a marginal role, a residual safety net for those who are not able to afford insurance or other means of securing their own health and social welfare needs; and (ii) run as much like businesses as possible. (p. 44)

This has led to the diminishing of the welfare state, trade unions and worker rights, while at the same time “combined with an attack on the idea that dependence can ever be a legitimate state” (Peacock, Bissell and Owen, 2014b). The expectations for responsible and resilient individuals is made more problematic when the infrastructural space and resource for collective action are diminished (Rose and Lentzos, 2017). For those from working-class backgrounds or where their material and financial resources are limited, the consequences of reduced state welfare and social safety net are stark, and I shall now move on to discuss how it can affect the way individuals and communities are perceived giving their relative position in this political arena.

2.4.2.1 Distinctions of Social Class: Social, Cultural, and Symbolic Capitals

Pierre Bourdieu resisted his work being drawn into the dichotomous argument of structure and agency (Jenkins, 1992). The concepts generated and utilised throughout his work, transcend the polemic to give a nuanced understanding of being in society. His concepts of capital attempt to both situate the individual and their resources within societal structures, whilst acknowledging that the individual may not be restricted to these. Considering the economic, social, cultural and symbolic capital that may be available to

them will help illustrate the power structures that belie the phenomena. These will be outlined below.

Firstly it is important to highlight the concept of symbolic violence. Bourdieu's conceptualisation refers to a mechanism by which the individual is unconsciously complicit in the reproducing of the structural division or hierarchy it creates.

It is an act of violence precisely because it leads to the constraint and subordination of individuals, but it is also symbolic in the sense that this is achieved indirectly and without overt and explicit acts of force or coercion. (Connolly and Healy, 2004, p. 15)

In attempting to identify this was occurring in the accounts of my participants, it will be required to note points of distress, conflict or tensions. These may be difficult for participants to identify or articulate. As Skeggs and Loveday (2012) highlight:

Lack of access to dominant symbolic moral authorization means that for those from which distance is drawn, those positioned as the abject as the constitutive limit to the good citizen of the nation, have few outlets for symbolic challenge. (p. 473)

Some might suggest that symbolic violence can be challenged. However, there must be awareness of it, and agreement of the negative consequences (Jenkins, 1992). Even when challenged, it may make no discernible change and therefore accounts, again, may not be overt in their explanation or example of attempts to resist (Skeggs, 2014).

The concept of symbolic violence is situated both in the internal and external. It is this that shall be evoked in the approach of this research. Some of the concepts in this research aim to go beyond an application of Bourdieu and situate the findings and work in the broader frame of sociological imagination and concepts. This broader usage of academic literature will help aid and understand the phenomena as they present, however doing so in a way that

helps circle the analysis and understanding back to latent power structures and symbolic violence.

Part of the reaction to the 'crisis of class' was a move away from thinking of class in only economic terms, but to consider the importance of culture. The 'cultural turn' (Crompton and Scott, 2005) aimed to take into consideration more than wealth and income. Based on the theoretical work of Bourdieu, Savage *et al.* (2015) suggest these are what might be described as the cultural and social signifiers. Social capital refers to the networks we have with the people in our communities, such as being friends with a builder or knowing a lawyer. These can indicate one's position in the social hierarchy. Cultural capital refers to the types of cultural activities that might be consumed or engaged with, such as being a football supporter or attending the opera.

Often linked with distinctions of social class, cultural capital refers to assets held by a person deemed to be of value by society of the time (Jenkins, 1992). For example, individuals having vast experience and knowledge of the high-brow, classical arts are considered to have high cultural capital. However, individuals having a vast experience and knowledge of football or reality television are considered to have low cultural capital as it is deemed as being less valuable in mainstream society to have this type of knowledge or interest.

Cultural capital highlights how social class inequality is reproduced (Bourdieu, 1984, 1989). Cultural capital would suggest that certain values and cultural practices are valued, and those who do not conform are considered to be distasteful. Bourdieu's conceptualisations are not without criticism. While attempting to bring the polarities together, he has been criticised for remaining overly objectivist.

The true explanation for actors' behaviour is seen to reside in the mysterious, murky depths of the habitus and, as consequence, 'choice' is largely underplayed. (Williams, 1995, p. 588)

The implication of the concept of habitus is that social actors are almost entirely ignorant of their decision-making processes and/or the set of societal structures within which they operate (Jenkins, 1992). Differences in cultural capital will add to this complexity and difficulty. It is therefore easy to see that this is a complex interplay of factors, and it would appear that the work of Bourdieu goes much further to acknowledge and explain previously dichotomous viewpoints of structure and agency (Christensen and Carpiano, 2014; Mcgovern and Nazroo, 2015).

In postulating about how social order and restraint are reproduced implicitly, and without explicit resorts to social control, Bourdieu described characteristics of class by the concept of symbolic capital (Jenkins, 1992). This is understood to refer to the honour, prestige or status that may be held. The deficit of these attributes and practices come to be perceived as vulgar and common (Atkinson, 2015). This is inextricably linked to social capital as it is “governed by the logic of knowledge and acknowledgement” (Bourdieu, 1986, p. 257) and is, therefore, a reciprocal process.

Beyond the cultural importance of class, Sayer (2005) notes that we are beings that make continual evaluative judgements. To this end, there are moral sentiments bound up with differing classes that are reinforced by their position:

Class contempt and moral boundary drawing exacerbate the effects of class, but distributional inequalities in access to valued practices and goods in any case render equality of conditional recognition impossible. (Sayer, 2005a, p. 960)

In casual conversation there can be discomfort and embarrassment when talking about social class, Sayer (2002) notes this is due to the life-chances being strongly linked to the social class they were born into, and not their potential to achieve, and this reflects an unfairness that people would instead not acknowledge. The consequences of the moral sentiments and significance attached to class position have been worryingly noted: “with the reduced level of social capital and interaction we get a reduction in the scope for compassion” (Thompson, 2016, p. 44).

Taking the attachment of moral value to social class position seriously, there has been much work undertaken recently to evidence the impact of stigma (Tyler and Slater, 2018). Understanding the lived experience of those are subject to shaming and stigmatising characterisations, such as asylum seekers, young people, 'chavs':

They are transformed into symbolic and material scapegoats for the social decomposition effected by market deregulation that has a negative, degrading impact upon us all. (Tyler, 2013, p. 211)

These characteristics can be known and felt to be negative and can, therefore, lead to one undertaking work to disavow and define oneself against those assumptions (Skeggs, 1997; Scambler, 2018a). Yet caution should be noted as these categorisations are not self-ascribed and in fact force persons to define "an identity produced through the disidentification with a pejorative class name posed from outside" (Tyler, 2013, p. 169).

In her influential work Skeggs (1997) highlighted the effort and lengths that women went to in order to position themselves as being 'respectable' and noted:

Sometimes desire for value reproduced the very distinctions they were trying to avoid. Respectability was used to make the movement in and out of the local, to increase their tradable assets, to generate distance from the representation of them as pathological and to claim legitimacy outside and inside the local. (p. 161)

2.4.2.2 Symbolic Violence and Resistance

Not only within academic circles is the view on social class and inequality uncertain, but there is evidence of an ambivalent attitude towards inequality and social structure (Irwin, 2016). Atkinson (2015) describes the process and effects of symbolic violence on those dominated by those in more powerful positions:

*There may be resistance and struggle, they may well value and rationalize their own way of doing things, but they still recognize – or rather **misrecognize**, since it is arbitrary – that, overall, the activities of others are defined as more legitimate or worthy and what one needs to do to ‘get ahead’ [...] Being compelled to see one’s life and lifestyle through the denigrating lens of someone else. (p.69)*

We should treat the conceptualisations of class, as pertaining to economic, social, cultural and symbolic capital, with caution and push back any attempt to utilise them as descriptors of empirically observable phenomena, but rather see them as metaphors (Skeggs, 1997). Often prescriptive thinking around class stops us from seeing the points of resistance. Both Tyler (2015) and Skeggs (1997) note that the Bourdieusian theory of class and capital does not leave space for understanding where individuals and communities may reject the othering their practices. By only framing those attempting to generate value through their action and practices, as deficient, lacking or void, it disallows any space for new meaning and value to be generated: “their value is their suffering” (Skeggs, 2011, p. 502). To only see the lives of those we engage with, in these terms is not only saddening but patronising.

To conceive of stigma and shame as a one-way process that cannot be countenanced would be misguided. While due to neoliberal rhetoric and discourse there has been a decline in solidarity, and an internalising of social and economic failures as personal, there are mechanisms of resistance (Peacock, Bissell and Owen, 2014b):

‘Collective imaginaries’ may provide part of a repertoire which explains, defends and rationalises our place in the world to ourselves and to others, and, crucially, may also offer a means of protecting the self against the symbolic violence that inequality can engender. (p. 396)

Community access to histories and narratives that enable and empower pride would be essential to deflect and resist the stigma that class relations in a neoliberal era seem to inevitably force upon society.

The power structures that guide and divide society may be latent, and much has been done to invisibilise the community and collective suffering and injustice, but just because terms and concepts may be contested or slippery, does not mean we should not and cannot speak to them and evidence their impacts.

I began this book expressing my fear that I did not know enough hard-core economic jargon to talk meaningfully about class. However, my silence, like all our silences about class, easily becomes part of the collusion, part of our acquiescence and participation in unjust economic practices, an unwitting support of class elitism. (hooks, 2000, p. 163)

This discussion of social class and the debates surrounding the term and its application are bound to continue. Nevertheless, it is vital to understand the concepts that surround it. Bourdieu does offer some insight into a culturally and symbolically nuanced understanding of structure and agency, which will be insightful to apply to the understanding of socially classed differences in death, dying and bereavement. However, the application of his theoretical work has its limitations, and that will be key in providing an attentive analysis of the findings of this research.

2.5 Inequality, Social Class at the End-of-Life and in Bereavement

2.5.1 Inequality at End-of-Life

Despite significant advances in medicine and care and concomitant improvements in life expectancy, it is still the case that in the UK there are class-based differences in mortality, morbidity and access to healthcare services amongst the population. This has become an area which has prompted much research and analysis and led to calls to policymakers and the NHS that this ought to be addressed urgently (Whitehead, 2007). Yet often there is little detail about the lived experience of those behind the trends, with the statistics frequently failing to give useful categorisations or move beyond limited data sets. This section aims to explore the qualitative

research that has noted or referenced social class as a significant finding in the sociology of death, dying and bereavement.

The statistics demonstrate that there is a difference at the end-of-life for those in the most deprived socio-economic circumstances. The outlined evidence suggests that there are continuing, and in certain areas, increasing inequalities between different groups in society, which is crucial for social and health agendas and policies to address and attempt to ameliorate. However, these categorisations can be arbitrary, and cannot and do not provide accounts of the lived experience of such a situation.

Quantitative research that produces statistics is socially constructed, designing and implementing classifications that can be generalising and reductionist, missing crucial variance and difference. In describing the standard quantitative treatment of class and race as variables to be controlled, Brown (1995) notes:

Populations are not random; they are stratified according to social structural features such as class and race. The context of this stratification means that the hazard exposures are not random, and hence we cannot accurately find universal dose-response relationships (Wing, 1994). Because of the stratification of society, hazards are inequitably grouped together and people experience them as collective assaults rather than individual probabilities. (p. 74)

Therefore, the statistical evidence should be treated with some caution. In using qualitative methods that explore the narrative accounts, experience and context in which the confounding factors which restrict or extend the availability of social, cultural and institutional support at the end-of-life is the focus and concern of this research.

2.5.2 Social Class and Death and Dying

A small number of classic studies highlight the different ways that social class and difference can affect the experience of death, dying and bereavement. These studies do not often explain an explicit approach to defining social class or attempt to operationalise it. However, McNamara (2001) noted:

Other aspects which contribute to the terminally ill person's ability to decide on aspects of care often relate to a number of socio-demographic variables, such as occupation, educational attainment, income and area of residence, which combine to give some measure of social class. (p. 62)

Young and Cullen (1996) undertook research in the East End of London to interview individuals with a terminal prognosis, as well as their family, friends and care-givers. In their study of the experience of dying Young and Cullen wished to understand the attitude that they felt was observable that a slow death is a 'better' death.

Support at end-of-life is portrayed as vital by Young and Cullen (1996), and it is clear from the very moving accounts that from providing care in the home to being able to converse with doctors on behalf of the ill, that this aid is pivotal to achieving a 'good death'. With particular reference to interactions with doctors and nurses, they note:

Working-class people have suffered the most because doctors have customarily thought of them as more 'simple', or that, with them, they can get away with it without their lack of compassion being challenged. (p. 116)

Far from being an isolated observation, it is noted previously by Seale (1998) that the awareness and control over the dying process are less open with working-class patients. McNamara (2001) also recounts an interaction she observed in a hospital between a doctor and a working-class patient, after the doctor had just been chatting with a patient whose occupation was a judge:

In this particular instance, the shared social status of the doctor and retired judge helped them to pursue similar communication patterns, and to find some level of agreement on issues regarding autonomy and decision-making. The gap between Patrick and Mick was far greater – the young man did not want to talk to the doctor. When Patrick asked Mick casually, 'How are you feeling mate?'

Mick mumbled, 'Have you ever died before?' and buried his head in his pillow. (p.62-63)

It is worth noting that Young and Cullen (1996), Seale (1998) and McNamara (2001) do not explicitly refer to social class as a focal point of their research. The lines of inquiry are not concerned with delineating and comparing the experience of those from relatively low socio-economic background. Yet, each has noted instances where differences arise that they interpret to be noticeably linked to social class or socio-economic status.

Further analysis of the work of Young and Cullen (1996) shows the participants in the research represent a range of differing backgrounds, occupations and level of education, as well as expressing varying values. The accounts given by the participants are very informative, insightful and moving, yet the analysis does not attempt to link these experiences and themes to wider societal constructs and hierarchical stratification. It provides a rich observational account of interviews with those at the end-of-life in East London.

The focus for Sudnow (1967) was how patients, and particularly those dying or deceased were managed by hospitals at a meso organisational level. His ethnographic, participant observation was undertaken at two hospitals in America. One hospital was located in a deprived area and predominantly used by working-class patients. The other hospital was in an affluent area used by middle-class patients. The way the two hospitals were accessed, and moreover, how they dealt with, treated and processed patients and those who became deceased was highly variable. The hospital in the working-class area demonstrated a higher incidence of emergency admissions and reduced patient and doctor interaction. Those unconscious or in a vegetative state were more likely to be treated as already dead, in that they were often left with little intervention for prolonged periods of time. However, this study again did not explore why these differences occurred. Sudnow (*ibid*) observed these differences in an anthropological manner and did little to couch the findings in broader theoretical concepts.

As previously discussed the influential work of Lawton (2000) did not seek to investigate social class; however, she noted that it was a visible marker of difference that remained with individuals even when previously defining aspects of identity such as gender had waned due to the illness. She suggests that this could be an example of how selfhood is not always defined by physiological or bodily states and:

One could thus see the retention of class attributes as being a further exemplar of this process of preservation of self from 'without'. (p. 169)

Lawton draws out the connection with Bourdieu's notion of 'habitus' to indicate that class attributes may remain once much of the self has disintegrated due to the 'naturalised' dispositions it forms. Yet, she does not fully explore why gender seems to dissipate as a marker of identity, yet class does not. Whilst this was not the remit of her work, it helps to highlight an observed difference that requires further investigation.

The ethnographic account goes on to describe how "notable" it was that staff treated their patients differently based on perceived social class differences:

Middle-class patients were, whenever possible, admitted to the privacy of side rooms, whereas working-class patients invariably found themselves allocated to beds in wards. One side room in the hospice was in fact informally name the 'VIP suite'; a term which meant, in practice, that the room was earmarked for members of professional classes. (ibid, p. 170)

2.5.2.1 Missing Working Class Voices

The experience of dying and how it affects identity leads some to produce reflexive accounts. It has been noted (Couser, 1997) (auto)biographical accounts often are representative of a particular viewpoint, namely, one which is intellectual/educated enough to produce coherent prose, and wealthy or affluent enough to be comfortable. Reflexive accounts are also more likely amongst those starting in a better state of health than one might imagine, as for people with rapid or unbounded deterioration such a venture

would be unthinkable. This could, therefore, be seen as a classed area due to the distinct lack of working-class voices and accounts.

In her ethnographic research of a foodbank in Stockton-on-Tees, Garthwaite (2016) noted that of the reasons people gave for their need to access a food bank a recent death of a family member was frequently cited. The loss could impact on their job security, finances, care responsibilities and in turn their bereavement. Work by Macdonald and Shildrick (2013) found that, whilst not designed as an area of probing, their interviews with young people living in disadvantaged communities in Teesside frequently elicited accounts of bereavement and related trauma.

The difficulties for those living in poverty to instruct and pay for a funeral has received limited attention despite the increased scrutiny of the media in recent years following from the reported rising cost. Research funded by Sun Life (2020) has stated that the cost of a funeral in the United Kingdom is on average £9,493. This represents a 42% increase on the cost in 2007. As far back as 1998, Drakeford was highlighting the lack of support and provisions for those who would struggle most to meet the cost of a funeral:

Both in terms of cash and in terms of eligibility, the scope of assistance has shrunk to the point where the famous promise of the welfare state must surely be regarded as broken. In the argument of this article, these changes have not occurred as a result of accidental fraying of the safety net. Rather, particular categories of individual have been knowingly and deliberately removed from the scope of assistance. In the market place such individuals find an industry which is increasingly inimical to their needs and, in a number of important ways, directly harmful to their interests.
(p. 523)

Whilst there has been some recent criticism of the lack of action on funeral poverty (Foster and Woodthorpe, 2013) and some tentative solutions with regards to promoting cultural acceptance of alternative and cheaper funerals

(Walter, 2017), it does not alleviate the worst distress for those facing bereavement of a loved one and exorbitant funeral costs.

2.6 Conclusion: Implications for Research

This wide ranging and expansive literature review has brought together bodies of knowledge that have previously remained separate and discrete. Some explanation has been sought as to why this may have been the case despite calls for the sociology of death, dying and bereavement to take seriously social class distinctions. In arguing that social inequality cannot be justifiably explained away as social difference, variation or disparity, this literature review has sought to reconnect an awareness of and the acknowledgement of the political landscape that differing groups of people and individuals reside in when facing a distressing part of the lifecourse.

It has been demonstrated that there are debates, discussion, and differences of experience at the end-of-life, and into subsequent bereavement. Where there is variation, there is potential for some to receive better or worse treatment of care, access to support or validation of their experience. Further concerns have been illustrated that the medical language surrounding death and ill-health has implications for the ways in which the living and healthy are required to conduct themselves and their lives (Banerjee, 2008).

Some of the most classic work around death and social class provides valuable insight and crucially helps to make clear an observed existence of a qualitative difference in the way in which individuals from different social classes can expect to experience dying and death. Class is used as a descriptive marker of differentiation without definition, further explanation, or critique. Furthermore, the research is a little dated and there has been a dearth of subsequent research taking these analyses further.

Calls for research in to explore the link between disadvantage and social class and death, dying suggests that it is essential as to understand this little known area in order that those from working-class communities are not neglected, and their experiences are given much-needed precedence (Lawton, 2000; Howarth, 2007b; Conway, 2013).

The literature review helps to demonstrate the need for further empirical qualitative research in this area. There is a great deal of evidence to suggest that health inequalities within the contemporary UK persist, with the most disadvantaged disproportionately affected by poor social, cultural and economic living conditions. Whilst the sociology of death, dying and bereavement has become a significant branch of academic interest and pursuit there has been a dearth of qualitative research to address the concerns around the working-class experience of this aspect of the life-course (Howarth, 2007b).

While there has been some acknowledgement and observation of the differences experienced by those from working class communities at the end-of-life and into bereavement, there requires a fuller investigation to ascertain the mechanisms that lie behind these descriptions of difference. It was noted that working class people appear to have less control over a good death (Seale, 1998), lack of research on the impact of the prevailing discourse (stage-based approach) on processing grief (Lloyd, 2018), and overlooking experiences of family members or friends closest to providing care (Knowles *et al.*, 2016).

Health and longevity become the archetype and norm by which illness, death and dying are regarded as abnormal and something to be feared. This can be seen to be the case especially with regards to illness that may lead to a terminal diagnosis, where some people today still refer to cancer as “the C-word” (Verjovsky and Jurberg, 2012). The insight provided by existing studies that have noted the significance of social class at the end-of-life has highlighted that rather than not being a significant factor, there is, in fact, much to question, explore and account for.

In discussing social class in the 21st century it has been outlined how the neoliberal form of capitalism is not only central to shaping class relations, but also is the underlying imperative by which individuals and communities are scapegoated, blamed and shamed for their relative disadvantage and stigmatised marking. End-of-life and grief as also seen as unproductive, and

therefore requires medicalisation and intervention. Yet, interventions do little to ease the suffering of those who do not and cannot access support.

The pallid and insipid version of [educational] social justice offered by the main political parties does not constitute social justice at all, but rather a watered down version of the elitism and 'racism of intelligence' (Bourdieu, 1998) that infuses most of the system. (Reay, 2012, p.596)

Whilst describing the education system, it is clear to see how this interpretation should inform our investigation of similar public institutions. The notion of social justice is one which can politicise otherwise observational research (Bordere, 2016). It is anticipated that this literature review has identified gaps not only in the literature, but also highlighted the need for an approach to undertaking research at the end of life and bereavement that is not only observational, but empathetic and challenging of the status quo.

Chapter 3: Methodological Approach to Undertaking Fieldwork in Death, Dying and Bereavement

3.1 Introduction

In order to situate the research undertaken to address the limitations of current academic understanding, as outlined in Chapter 2, this chapter will describe the work undertaken, both in terms of the epistemological worldview, and then the manner in which this informed the practical approach to fieldwork. Firstly, a discussion of the philosophical understandings of the nature of knowledge construction and the theoretical foundations will highlight how this research is framed. Next, the practical issues that shaped the design, methods and data collection will be discussed that were contingent to the fieldwork and analysis. As this research was flexible and reflexive the adaptations to the fieldwork will be described in detail to highlight how this aided recruitment of a greater sample than otherwise might have been the case.

Finally, the chapter will describe how the data was processed and analysed as the research unfolded, due to the nature of the serial or re-interview approach. This meant that analysis was ongoing throughout the fieldwork, and then also once fieldwork had concluded. At the end of this chapter, the manner in which this data is discussed in the following findings chapters, with regards to accent and colloquialisms, will be described.

3.2 Research Aims

As previously outlined in Chapter One and Chapter Two, the aim of this thesis is to explore the experience of death, dying and bereavement and the relationship to social class. This was as outlined by the call for doctoral studentship funding from the Foundation for the Sociology of Health and Illness. The interest arises from a dearth of investigation and understanding of the working-class experience at end-of-life and in grief, as was outlined effectively by Howarth (2007b). Whilst there has been a great interest in the physical and emotional impacts of death, dying and bereavement with structural difference and identity construction with regards to gender and ethnicity, there has been a fundamental oversight of working-class

experience, and as such, relies on a range of assumptions, including that those of the working-class will be “eager to adopt rituals that might be meaningful to those above them in the social hierarchy” (*ibid*, p. 430). This research undertook a series of narrative, semi-structured interviews with bereaved carers living in Teesside. Inspired by feminist methodological approaches, the research was designed to disrupt the traditional power asymmetry of the interviewer/interviewee and give those taking part a platform to describe their experiences.

3.3 Ontology and Epistemology: Constructionism and Realism

In order to make explicit the assumptions and traditions from which this research is produced, it is crucial to make clear the philosophical understanding of knowledge. This section will highlight that whilst there are positions which are presented as being fixed, often the edges are blurred or softened, and as such, the work takes a nuanced approach.

Crotty (1998) states that epistemology “is a way of understanding and explaining how we know what we know” (pg. 3). The ontological approach of the research is based, on a constructionist understanding of knowledge. This is the guiding ontological stance that knowledge is not found or discovered objectively, rather it is constructed. A definition of constructionism is offered by Crotty (*ibid*) as a “view that all knowledge, and therefore all meaningful reality as such, is contingent upon human practices, being constructed in and out of interaction between human beings and their world, and developed and transmitted within an essentially social context” (pg. 42). In taking this view, there is adherence to five underpinning assumptions:

1. The way in which we understand the world is not required by “what there is”
2. The ways in which we describe and explain the world are outcomes of relationship
3. Constructions gain their significance from their social utility
4. As we describe and explain, so do we fashion our future

5. Reflection on our taken-for-granted worlds is vital for our future well-being (Gergen, 1994)

A constructionist view believes that there is no objective truth to be discovered; rather, there are subjective interpretations and constructions based in interaction (Bhaskar, 1989; Maxwell and Mittapalli, 2010). Making meaning leads to interpretations that can differ and be effected by the social context or individual. However, there are no 'true' interpretations (Crotty, 1998). Whilst this inspires and reflects much of the approach to this research, it does not define the only ways to conceive of the study.

Having thought to be incompatible with of antagonistic of constructivism, Barkin (2003) notes:

Constructivists who claim their methodology is incompatible with realism focus on the association between realism and both materialism and rationalism. Realists who claim their paradigm is incompatible with constructivism focus for the most part not on the methodology per se but on a perceived tendency for constructivists to be idealists or utopians. (p. 325)

'Critical realism' and 'subtle realism' are different in accommodating of a complex reality. Critical realism states that our ability to know and study reality is limited and as such, is open to critique and scrutiny. Whilst, subtle realism notes that reality can only be known through subjective and socially constructed meanings (O'Reilly and Kiyimba, 2015).

One of the reasons realism and constructivism have been viewed as incompatible is their conceptions of power, and how power can be overcome. Jackson and Nexon (2004) push Barkin's argument further to state:

An obvious candidate is the post-structural and relational argument that power inheres in social practices, and that the (re)production of stable social relations is always a result of strategic (but not always rational) social action. In short,

power, by definition, is always present and implicated in any social formation. (p. 340)

The unifying commonality of these varied approaches to realism, as noted by Maxwell and Mittapalli (2010), is that they are all based on realist ontology. This asserts that there is a real-world and means that this real world can only be known from our own interpretations perspective (Bhaskar, 1989).

In stating their approach Ormston *et al.* (2014) note of realism:

We recognise the critical importance of participants' own interpretations of the issues researched and believe that their varying vantage points will yield different types of understanding. Our position is that external reality is itself diverse and multifaceted and it is the aim of research to capture that reality in all its complexity and depth. (p. 21-22)

This nuanced approach allows a clear acknowledgement of the underlying assumptions on the part of the researcher, and also that interpreting and understanding the world is complex and messy. It is this approach to realism, or realist-constructionism, that inspires the approach to undertaking research for my own endeavour, whilst keeping in at the forefront, the multiplicities of knowing, being and understanding, in relation to power.

Further to this, placing the debates regarding ontology, allows for consideration and examination, of epistemology. That is, of how it is best to know and understand the world instructs the approach one will take (*ibid*). An inductive approach believes that knowledge and theory is the *outcome* of research, as opposed to a deductive approach which states a theory and then seeks to prove or disprove it (Bryman, 2012). Whilst this research does not seek to propose a hypothesis, and through an inductive approach aims to iteratively observe and present the knowledge gathered in the field, it is key to note “when so-called inductive researchers generate and interpret their data, they cannot do this with a blank mind” (Ormston, 2014, p. 6). In light of my constructivist sympathies, it would be short-sighted and illogical to claim that the research is entirely inductive. This chapter will reflect upon and

situate myself as a person and a researcher in the work in preceding sections.

3.3.1 Operationalising Class

As was highlighted in Chapter Two, social class is a contested concept. As this thesis seeks to explore, at the very centre of the research questions, the issue of social class, it is important to situate the approach to this ubiquitous yet sometimes oblique concept. There is little consensus on a universal measure of social class (W. Atkinson, 2015), or the value in attempting to 'measure' class (Coburn, 2004). In recent years the term "working-class" has been used interchangeably with and is associated with many other terms, including; "poor", "poverty" and "disadvantaged" in qualitative work, and "socio-economic status" and "most deprived quintile" in quantitative work (Scambler, 2018b).

There are many ways in which social class and "working-class" could have been operationalised for this research project. A great deal of thought went into how, in practice, it would be best to conduct fieldwork with the concept pivotal as part of the research questions, yet still allow recruitment for a sensitive topic to be carried out.

The variety of measures focus upon different factors including income, occupation, level of education, parents' background, geographical location, leisure activities, lifestyle or food consumption, etc. It was judged to be remiss in picking a measure that could narrow the scope of the research, as this could have potentially limited the number and range of participants that were recruited.

It was clear that imposing an objective, pre-determined social class categorisation of potential participants as part of the eligibility criteria may also prove problematic for gatekeepers. By defining social class, it would have required a decision by gatekeepers as to who then would be recruited. As the recruitment was opt-in and done through trusted gate-keepers, whom themselves are very busy, this could have potentially required an additional action by them. It would have been additionally problematic to ask staff distributing information packs to assess the class of the person whom they

had identified as meeting all other aspects of the eligibility criteria. Criterion sampling, in this instance, limited and hampered the recruitment process, without having a justifiable impact on the end results (Bryman, 2012).

As an alternative, subjective self-identification of social class was considered. However, I deemed that it would not be appropriate to ask potential participants to identify themselves as a particular class prior to interviewing. Savage *et al.* (2015) highlighted:

Most people now are ambivalent and hesitant about which class they belong to, and when quizzed about it often prefer to reflect on the way they straddle different classes. (p.366)

Evidence suggests that surveys and polls on social class identification produced varying responses. The British Social Attitudes survey (Evans and Mellon, 2016) found that 60% of those asked identified as working class. However, another online poll suggested that 71% when asked identified as middle-class (Shimshon and Mattinson, 2011). There may also be a desirable (or undesirable) factor to proclaiming belonging with a particular social class. Beyond the quantitative variation, Skeggs (1997) evidenced how, in their discourse the women she interview distanced themselves from class identifiers, despite social stratification and class playing a significant role in shaping their lives. Savage (2000) notes the “paradox of class”, whereby despite evidence highlighting the importance of structural differences, it is not self-consciously experienced at a cultural level. This may indicate that class consciousness and requiring people to categorise themselves may be not entirely accurate, and to exclude participants based on this might have been detrimental to the research.

In order, to avoid either participants’ self-identification of a social class, or a researcher imposed social class, the decision was taken to recruit participants according to geographic location. The constituent boroughs of Teesside (Middlesbrough, Stockton-on-Tees, Hartlepool, and Redcar and Cleveland) are ranked as some of the most deprived boroughs of the country. Those participants recruited from this area can, therefore, be viewed

as being part of a “disadvantaged community”. Participants’ deprivation quintile is highlighted as part of the findings chapter and appendices.

In recruiting within a geographical area, the range of potential participants would cover a spectrum of social class experiences. Whilst the focus of the research is to explore the experiences of those from working-class communities, having a range of accounts aids the understanding. By posing the same questions and allowing participants the same opportunities to share their experiences, the narratives given allow for cross-comparison of themes and incidences. This helps to strengthen the research as it does not rely on assumptive notions of middle-class experience from secondary sources.

Using geographical area to draw a sample population from, rather than a pre-defined measure of social class means that an arbitrary factor did not omit persons who wished to share their experiences. This avoids pre-determining the complexities of social class. This is important not only in the recruitment but also in setting aside stereotypes and assumptions of the experiences of participants. It was important to ensure this was the case in order that an experiential view on a social phenomenon that has hitherto received little attention (Howarth, 2007b), was able to be given the space and platform to be heard.

In keeping with recent work by Tyler (2013, 2015) and Skeggs (1997), this research aims to uncover latent power structures and social hierarchies. In doing so, it does not seek to place people in strict categories, from which it is assumed they will be indelibly marked forever. But instead, it seeks to explore and situate the accounts as they are presented and seek to illuminate the consequences of their perceptions and experiences.

In line with the constructionist ontological position, this research does not claim to provide a ‘valid’ or ‘true’ interpretation, but an interpretation which is underpinned by a reflexive, dialectical approach to undertaking robust research with willing individuals to elicit their experiences.

Understanding the circumstances of those participating in the research is necessary in order to fully appreciate the privileges and allowances afforded to them or constraints and limitations that may characterise their ability to

navigate through a difficult aspect of the life course such as caring for someone at end-of-life, the death, and the subsequent grief and bereavement they are faced with. Whilst these events will be similar for all, they will be situated differently from one another.

3.4 Research Design

3.4.1 Narrative Feminist Epistemological Approach

This research was influenced by feminist methodological approaches to undertake qualitative research that was embedded in the community, in a sensitive and respectful manner, and allowed for an active disruption of power asymmetries often associated with qualitative research. In giving space for the participants to describe and narrate their experiences at length, this research aimed to give them a platform that did not seek to curtail the moment to suit a prescriptive research method. In order to do this mindfully, the approach was inspired by the description offered by Back (2007) on the importance of listening:

In involves artfulness precisely because it isn't self-evident but a form of openness to others that needs to be crafted, a listening for the background and the half muted. (p. 8)

The following sections outline the pragmatic approach taken to gathering the data and findings presented throughout this thesis.

3.4.2 Identifying the Research Setting

The empirical work was conducted in two stages. Firstly, a series of scoping interviews with local stakeholders, such as charities and support agencies took place. Stakeholders were identified through various means. An internet search took place in order to understand some of the available services in the area regarding end-of-life, bereavement and what carer support organisations were available. I then began to make contact via email or telephone with identified stakeholders, outlined the area of interest of the research briefly, and enquired if there would be time and interest in having a telephone call or meeting to allow me to understand their remit and aims.

There was a positive response, and I met with a range of organisations. This gave me a better idea of the provision of support for carers in the region, and where some of the gaps might be regarding the oversight of bereaved carers (as will be discussed further). Additionally, there was some snowballing of contacts made, and those I met with frequently suggested others who might be interested in the research I was undertaking, or I might be interested to learn more from.

Some of the identified stakeholder organisations included; Sanctuary Carers, Darlington Association on Disability, Carers Together Redcar, George Hardwick Foundation, Teesside Hospice, Butterwick Hospice, Citizens Advice Bureau, Middlesbrough Council, Hartlepool Council, Fabrick Housing Group and Tandem Financial Advice Service.

This stage of the research was important not only to aid subsequent recruitment, as some acted as gatekeepers, but to inform and understand the services and organisations that provide support, or impact upon the lives of those who are terminally ill, or care for someone who is end-of-life, but are separate from the NHS.

3.4.2.1 Teesside in Context

Historically the Teesside area of the North East of England has its roots and modern legacy in the industrial revolution. Stockton-on-Tees was known as a primary market town for the area, but the birth of the railways transformed it, as it did Darlington, by linking the two towns with the world's first railway line in 1825. In Middlesbrough, the discovery of iron ore in the Eston Hills played a part in seeing the town increase from a population of 40 in 1829 to over 20,000 by 1860 (Simpson, 2018). Having also acted as a port for the export of coal from South Durham until the 1850s the early heritage of this town and area was born of hard manual and skilled labour. Teesside is typified as an area with a historical legacy of industry, and was well known for the production of iron, steel and shipbuilding industries (Garthwaite, 2016).

The manufacturing industry has been at the heart of the economy of Teesside and the cause for much of the establishment of neighbourhoods and growth of population since the early 19th century.

Even today many residents of Teesside have connections to the industry, whether it is having worked in it themselves or having had family members that did. It is a unifying form of employment for the area. One which provides a sense of pride and achievement for the diligent and productive reputation the area came to be characterised (Lloyd, 2013). However, for the majority, this is an occupation or career that has become increasingly inaccessible due to rapid deindustrialisation beginning in the 1970s.

A cluster of factors contributed to the decline of industrialism across much of the UK and is evident as having effected Teesside. Technological advancements saw the work of labour force decrease as people were replaced with machinery. In addition to this, global competition undermined the outputs of the region and saw the manufacturing leave the banks of the River Tees can go abroad to take advantage of cheaper labour (Garthwaite, 2016). Both of these factors were underpinned by rapid deregulation in the 1970 and 80s by a Thatcher government which allowed the former events to transpire and progress, with little in the way of a meaningful fightback from workers or unions (A. B. Atkinson, 2015).

3.4.2.2 Current assessment

The recent history of Teesside is much less encouraging than its inception. It is suggested that there was an over-reliance on industry with “investment and expansion in a narrow industrial base” (MacDonald and Coffield, 1991).

Attempts to revive Teesside’s economy has offered little that is comparable with the previous skilled labour. The rapid growth in the low paid service sector has seen the workforce change, with some struggling to come to terms with the new employment landscape. Even so, there is a chronic lack of jobs in the area and, as an example, in 2015 a hotel chain in Middlesbrough advertised six posts at a jobs fair for which they received over 500 applications in under five hours (Cain, 2015). Arguably the service sector roles that are now the dominant aspect of the labour market does not go far enough to give meaningful employment to a once skilled and highly demanded workforce.

Inequality and poverty are pronounced on Teesside, and the area frequently features in some of the starkest evidence of disparities both within the region, and on comparatively with the rest of the UK.

The Census revealed in 2011 that Middlesbrough had one of the highest rates of workless households at a rate of 23% compared to the National average of 9.9% (Ruddy, 2011). The number of food bank referrals have increased at an alarming rate, across the UK the number of emergency food parcels supplied increased 919% between 2011/12 to 2016/17. Whereas, the North East saw a percentage increased across the same period of 8309% (Community Foundation, 2017a). When using a crime score (calculated by looking at average rates set crimes per population), every locality in Teesside is significantly higher than the national baseline of 100, with Middlesbrough recording the highest crime score at 181.95 (Community Foundation, 2017b). It is estimated that in the North East investment in public transport is likely to be £3,117 less per person than in the affluent South East based on proposed government spending (Raikes and Lockwood, 2019). The evidence further suggests that those living in Teesside are more likely to experience indebtedness, fuel poverty, and more like to have children who are eligible for free school meals, than the national averages (Community Foundation, 2017a).

Health inequalities are entrenched in Teesside and the North East. In the town of Stockton-on-Tees, the life expectancy gap between residents is the most stark in the UK, with a 17.3 year difference for men, and 11.4 year difference for women (Garthwaite and Bambra, 2017). The North East consistently has high rates of suicide and the most recent statistics highlight it has the highest rates in the country of suicide amongst men, 20.4 deaths per 100,000 (Gullon, 2019). This profound difference in mortality rates was highlighted by Whitehead (2007):

There is a steeper social gradient in health within the North than in the rest of England meaning that there is an even more significant gap in health between disadvantaged and

prosperous socio-economic groups in the North than in the rest of the country. (p. 6)

In *Get Rich or Die Young*, a BBC documentary aired in 2018 a local undertaker, Alison Crake, described her thoughts on Stockton based on her work:

You look, and you see somebody's age, and you think that that's far too young. It goes beyond the initial grief of losing somebody you love and who is a key part of your family, because it reaches out into all the years that follow. (Bilton, 2018)

3.4.3 Recruitment

In attempting to design the empirical research, the overall project underwent several significant changes and reiterations, which I believe is to the benefit of the resulting fieldwork and subsequent findings.

Initially, the research aimed to recruit from hospices' working-class individuals who had a terminal diagnosis. This approach was deemed to be problematic for a number of reasons. There has been evidence to suggest that hospices tend to cater to a more middle-class population (Lawton, 2000). This could potentially be for a variety of reasons including; the way in which patients are referred to a hospice; the setting and processes within the hospice; and the perception of hospices by potential patients.

In scoping and speaking with managers at two local hospices, they noted that whilst they did draw from and reflect the local community that their patients did tend to reflect a more affluent socio-economic background. Whilst it is not the focus of this research, it is interesting to note that there were some reflection and indication that those patients, and their families, that were perceived to be from working-class backgrounds presented more complex familial situations which were difficult for the hospice to handle within the remit of palliative care. As interesting as this may have proved, it was felt that this was not the appropriate site of research to understand the end-of-life experiences of those from working-class backgrounds.

Another reason for not recruiting through hospices was that they often cater to a particular illness. Hospices primarily administer palliative care to those at the end-of-life. Yet determining if someone is end-of-life can vary dependent on the disease or illness for which the individual is being treated. The trajectory of an illness can be variable, yet as Murray and Sheikh (2008) highlight, cancer has a very different decline. The end-of-life stage for cancer is usually shorter and more predictable, and therefore often easier to apply palliative care services to. Hospices have often been charged with not extending their palliative care enough beyond the treatment of those with cancer. In 2013/14 of those who received inpatient or day hospice care at Teesside Hospice, based in Middlesbrough, 79-91% of those had a diagnosis of advanced cancer (Teesside Hospice, 2015).

Whilst it is acknowledged that cancer is one of the biggest causes of death in the UK, cancers accounted for 30% of deaths in men and 24.8% of deaths in women in 2015 (Public Health England, 2017), it is essential to look beyond to understand experiential accounts from a variety of deaths. Taking into account this arguably narrow reflection of disease treatment, it was decided that by not recruiting through a hospice, the research would potentially recruit participants whose experience reflected a more extensive range of end-of-life trajectories.

In addition to this, there were some differences of approach within the supervisory team. This took some time to overcome, and a change of the supervisory team was required to reflect the best way to progress the empirical research. Once resolved, it followed that resource constraints would not allow enough time to undertake the required NHS ethical approval procedure, which is known to be a lengthy process. Therefore, it was decided to focus on carers of end-of-life patients instead.

It is believed that there are approximately 6.8 million carers in the United Kingdom (Buckner and Yeandle, 2015), which represents approximately one in ten of the population. Informal carers were defined in this study as individuals who had provided care to a family member or loved one, who had no formal training, and may or may not have been in receipt of social support

and/or financial welfare. This social support may have been in the form of formal carers or district nurses.

As the aim of the research was to gain insight from the experiences of informal carers who have been recently bereaved, this gave defined boundaries to the sample population. Yet there was no restriction placed on the type of illness for which had been cared for. This allowed for a plurality of experiences to be represented in the data. Potential participants were simply to identify with the experience of having lost a loved one for whom they had provided care for. There was no time period for which the caring role must have taken place and no criteria by which the end-of-life period had to be prolonged or sudden. By doing this, it allowed the research to capture pluralities of perspectives which may have otherwise have been overlooked.

3.4.4 Gaining Access

With a sample population defined and initial scoping of local stakeholder(s) groups recruitment could start to be considered. Recruitment for the research was planned with the safeguarding of potential participants in mind, which will be discussed further as part of the section on Ethical Considerations. Access was negotiated through established links with relevant local agencies.

Gaining access to a sample population required identifying potential 'gatekeepers'. This term refers to those persons who "have the power to grant or withhold access to people or situations for the purpose of research" (Burgess, 1984, p. 48). In practice, this was not particularly straightforward, as will be discussed here.

Whilst negotiating access, I developed a working relationship with a local carers organisation called the George Hardwick Foundation. This helped to provide an insight into the backdrop of the provision of carers support services in Teesside (specifically Stockton-on-Tees in this instance). Their feedback also helped inform the ethical application and ensure that appropriate safeguards were put in place to protect the wellbeing of any potential participant.

Unfortunately, just as the research gained ethical approval, their funding was stopped, and they had to close. Despite this fieldwork set back I was

compelled to investigate other potential gatekeepers beyond community-based carers organisations, including community support groups, charities, funeral directors, social services, social housing providers and faith or spiritual leaders.

Throughout the process of negotiating access and recruitment, it became clear that, as a sample, bereaved carers proved to be challenging to identify and reach. This is not to indicate that there are not many recently bereaved, carers, but rather that the community-based organisations through which I was attempting to recruit through did not have sustained contact with, or found it difficult to identify potential participants.

Whilst scoping the local region for assistance available for bereaved carers it became clear that there are no dedicated organisations or services in the region that provide a specific support package for those whom have taken a carers role and are now bereaved. These organisations were often upfront in stating that their work did not usually permit much contact or access after the death of the family member. Often carers support services indicated that they would like to be able to provide support when carers became bereaved, but funding constraints did not allow for this. In fact, it was noted despite the significant commitment and labour that many informal carers take on, as a group of people they are often “forgotten about” once their caring role has ended. These conversations often ended without identifying a specific population for the research to sample from, but with a keen interest in the findings and results from these organisations, hoping to be able to take action from these findings.

Additionally, the bereavement support agencies, religious groups, financial advice and funeral services that acted as gatekeepers also found it difficult to clearly identify potential participants, as they would often provide service or give support to anyone accessing or referred, regardless of their care (or non-care) role. Whilst there appeared to be interest from these organisations to identify potential participants, none of the participants finally recruited into the research were referred from a bereavement support agency.

Due to the variety of gatekeepers that fed into the recruitment process, the range of illness and death experiences was multiple. A great deal of previous empirical work has drawn samples through medical settings, with samples potentially being drawn from one department or hospices (Sudnow, 1967; Lawton, 2000). Using a range of community-based organisations, charities and spiritual leaders permitted access to a range of illness experiences. This highlighted differences in experiences as will be discussed in the findings chapters.

However, recruitment was challenging and necessitated a flexible approach. Based on the feedback of gatekeeping organisations in the field, and also of the participants themselves several changes to recruitment and materials were made. The approach was continually under review and adapted in order to maximise the opportunity for potential participants to take part in the research. All changes that were made to the recruitment process were submitted for and approved for ethical amendment. This included reducing the length and size of the recruitment pack and materials, adding an option of telephone interviews, and increasing the methods by which potential participants could contact the researcher. I explain these changes in more detail below.

A poster (Appendix 1) and leaflet (Appendix 2) were designed using the information and text from the participant information sheet to provide a shorter method of communicating to potential participants. This was designed to be put in waiting areas or notice boards of organisations that may come across bereaved carers, such as the Citizens Advice Bureau, funeral directors, carer support organisations, religious groups and end-of-life and illness related charity shops.

I attempted to use snowball sampling. In interviews where it was felt that the participant generally responded positively they were asked at the end if they knew of anyone in their networks of friends or family who might be in a similar situation of having cared for someone who subsequently died. If they did, they were asked if they would be willing to pass on either a leaflet

explaining the research, or my contact details in order to be sent a participant information pack.

As the project progressed and from some of the feedback of the organisations and participants themselves, it was clear that there was a feeling that many people who are providing care may not ever come into formal contact with carers or social services, and therefore may be outside the scope of the research. In order to attempt to widen this scope, social media was used to disseminate information about the research through localised Health Watch Boards (varied panel of members from the locality which aim to act as a champion for improvement of population health and the organisations delivering health services). Approval was sought for and granted through an ethical amendment.

A particular part of the eligibility criteria that was altered was the time period from which the carer was bereaved. Initially, this was from 3 to 12 months from the death; any sooner than 3 months was considered to be potentially be too emotional raw a time for participants, and initially the concern was felt that any longer than 12 months might mean that participants would not adequately remember and be able to reliably recount their experiences. After some consultation with my supervisors and feedback from local bereavement organisations, the decision was taken to extend the time period to 2-3 years. This proved to be a good decision as unprompted feedback from participants indicated that they did not feel in hindsight that they would have taken part in the research had it been in the first 12 months of their bereavement as they would have anticipated that it would be too difficult emotionally for them. This also received ethical approval after being submitted as an amendment.

In order to encourage any potential participants to come forward, a project mobile phone was set up to increase the ease of access to contact. This was a separate mobile phone from any personal mobile but allowed potential participants to contact me either by calling direct or by text message. This proved to be a useful method of communication.

Potential and recruited participants were offered the option of telephone interviews. However, all participants agreed to be interviewed in their own homes at a time that was mutually convenient.

Once participants had expressed their interest, an initial interview was arranged at a venue to suit the comfort and needs of those taking part; in all cases for this was the participants home. In order to minimise risk, I adhered to the Teesside University 'Lone Worker Policy'. Participants were asked to read, initial and sign a Consent Form (Appendix 3) before the interview commenced. All interviews were recorded on a Dictaphone.

After the initial interview participants were invited to take part in follow-up interviews at an interval of 2-3 months. Participants were made aware that they were not obliged to take part in any subsequent interviews. Rolling consent ensured participants were aware of their rights to confidentiality and to withdraw. This reconfirmed that the consent remained valid.

Given the deeply personal nature of the accounts given by participants, efforts have been taken to protect their confidentiality and identity. It is not claimed that these accounts could ever be anonymised, without losing the validity and veracity of what participants have said, in their own words. However, some identifying features have been either pseudonymised – such as participant, and all accompanying family names – or have been made generic – such as not disclosing names of specific hospice, or disclosing participants exact age. Whilst all participants willingly consented to participate and signed associated consent forms, it remains imperative that as a researcher, I treat their accounts with sensitivity and care.

3.4.4.1 Using gatekeepers

I liaised with the gatekeeper organisations that agreed to take part in this research. These organisations were briefed by the researcher in a discussion, or either at a staff meeting or by a briefing document aimed to explain the purpose, remit and methods of the research. They were asked to use their judgement in order to identify potential participants in line with the eligibility criteria outlined below. Those deemed to be eligible to be potential participants for this study must:

- Be over the age of 18
- Be capable of giving informed consent
- Be living in the Teesside area (the boroughs of Stockton-on-Tees, Middlesbrough, Hartlepool, Darlington, and Redcar and Cleveland)
- Have provided informal care (for which they may or may not be in receipt of Carers Allowance benefit) to an adult family member, spouse, or close friend who has been deceased for a minimum of 3 months, up to 12 months (this was later extended up to 2-3 years, which will be explained below)
- Have had contact/advice/support from one of the gate-keeping organisations/persons

Gatekeepers determined who they believed fit the eligibility criteria and distributed an information pack which included; an introductory cover letter (Appendix 4), a Participant Information Sheet (Appendix 5), which explained the process of taking part, their rights to confidentiality, how to withdraw, and how to contact the researcher if they have further queries or wish to take part. The pack also contained an Expression of Interest Slip (Appendix 6) and pre-paid self-addressed envelope for potential participants to opt-in to the research. In addition, potential participants were able to express their interest to take part in the research by contacting the researcher directly on the contact details provided (email, office landline telephone number and fieldwork mobile telephone number) and by giving the Expression of Interest Form to the gatekeeper organisation/person.

A change to the eligibility criteria that proved to be valuable was to increase the length of time since the death. Initially, this was those who had lost a loved one for whom they had cared between 3 and 12 months ago. This was based on a concern that those who were any closer to the bereavement may be too raw emotionally to not bring further upset. The limit of 12 months was based on a concern that the recollection of participants may not be as reliable.

This was increased on the flyers to 2-3 years after only a limited number of expressions of interest were received to provide further flexibility for

recruitment. After doing this, a number of participants were then successfully recruited at a 2-3 year point since their bereavement. Some of these participants commented that, if they had been earlier into their bereavement, then they would not have taken part in the research. Additionally, given the closeness and intimacy of the caring role, the retrospective accounts rarely faltered or paused to recollect detail as they were still remembered viscerally.

In light of discussions with participants and gatekeepers, a change was made to the participant information leaflet to explain to potential participants what a 'carer' was. It was noted that some might not identify with the term, or see what they do as being a 'carer' role. Additional duties and responsibilities often build up gradually, and they are undertaken out of a sense of familial responsibility, duty and care.

Several participants were recruited through colleagues or friends who were aware of the research that I was doing. This gave me access to narrative accounts that I would have not otherwise have been able to represent in my findings.

3.4.5 Qualitative Serial Interviewing

Interviews with bereaved carers were based around a narrative, storytelling mode (Gunaratnam, 2009). Initial interviews informed further serial interviews, as was appropriate, and where consent was given to do so. Participants actively conversed to produce their narration of eventing: this included from the initial onset of illness of the person they cared for, their death, and up to and including the point at which the participants were interviewed. I initially planned to follow up with subsequent interviews at 6-12 week time periods; however, sometimes due to busy schedules or other issues (see my findings chapters), this could take longer. Participants were interviewed a maximum of three times in total if the participant was contactable, able and willing to take part. Three was decided as the limit based on the final number of participants recruited being 13, to make the management of lengthy interviews, and therefore a great deal of data, more feasible within the time constraints.

The time between interviews allowed for transcription and familiarisation with data, and emerging analysis to be carried out. This allowed for reflection upon the data and the ability to formulate follow up lines of inquiry, and questions for the next interview. Most importantly it allowed me, as the researcher, the opportunity to build rapport and insight, and to track the way in which sense is made of the death and dying experience by the carer over time.

In the initial information presented to participants regarding the length of interview time, an estimate of an hour was given. However, given the sensitive nature of the interviews, it was essential to allow participants to take their time to narrate their own experiences at their own speed. Participants were aware that if at any point, they wished to pause or end the interview that they could do so. Participants were made aware that follow up interviews were likely to be more directed by the researcher, with questions arising from their initial accounts and of experiences recounted by other participants also.

In total, 29 interviews were conducted with 13 participants. Some participants were interviewed two or three times. Only two participants were interviewed once (Ian and George). Interview length ranged from 52 minutes to 163 minutes. The average length of the recorded interview was 117 minutes, just under two hours. The interviews were conducted between April 2014 and December 2015.

3.4.5.1 Narrative Semi-Structured

The conduct of interviews most closely reflected that of the experience-centred narrative approach (Squire, 2013). This approach meant that, in being invited to interview, participants were not necessarily opting for one interview, but rather multiple, if they felt so comfortable to do so.

Whilst there is not a single agreed upon term, the use of many interviews with research participants is a well-established if overlooked qualitative research method. Referred to as serial, follow-up, or re-interviews, as well as being described as post-interview interaction, there are multiple ways to utilise interactions with participants after an initial first interview (*ibid*). It has

been noted that, as a method, serial interviews have previously been underutilised.

Where serial interviews have been used, they have proven to be effective in eliciting in-depth, personal accounts. Serial interviews are of particular value in social science and qualitative health research when aiming to gather data that captures two types of phenomena. Firstly, this method is useful when attempting to understand a longitudinal process. By the nature of seeking to gather further data at a future point in time, serial interviews have been successfully used in medical research where it has been pivotal to understand how a patient's experience or feelings may change over the time of being ill (Murray and Sheikh, 2008; Lewis *et al.*, 2014). Secondly, serial interviews are beneficial in the investigation of topics of a sensitive nature. Subsequent interviews allow the opportunity of trust and rapport to build between the researcher and participant. When participants are made aware that they will be interviewed more than once there is a more flexible approach in which participants may begin to feel like collaborators, as opposed to one-time, "hit and run" interviews in which they may simply feel like sites of data.

Sensitive topics are often discussed within qualitative research guides as requiring a careful approach (Milne and Lloyd, 2009). Due to the sensitive nature of the research, it was deemed appropriate to use serial interviews. Given that the research aimed at understanding an aspect of the life course frequently considered taboo, and from the perspective of carers from disadvantaged communities, it was considered advantageous to use a method that would promote trust in a receptive interview setting, and also have the potential to capture and draw focus to change and transformation over time.

A particular strength of undertaking interviews which aim to be repeated is that it allows space for narrative accounts to develop relatively uninterrupted or prompted. When designing the research, it was felt that giving potential participants conversational space would allow for a rich description of memories and experience. As Squire (2013) notes:

Re-interviews and other post-interview interactions can also be viewed as ways to give interviewees more power over their materials; to enable them to 'look back' historically, or to continue the conversation. (p. 56)

Rather than a specific interview schedule of narrow questions, a topic guide was designed (Appendix 7). Initial interviews with participants were flexible and avoided questions in favour of themes and prompts. Participants often took the lead in telling their stories and with little questioning required initially. Arguably participants felt comfortable taking the lead in conversation as they were aware of the expectation of them and the interest of the research. This would have been helped by the information they had received and by the telephone conversation prior to interview for arranging a suitable time and location for the interview to take place.

Giving participants the space to lead their narrative in a reasonably unconstrained manner was acceptable in this circumstance due to the use of serial interviews. Participants were reminded that they would be asked if they would be happy for a subsequent interview and at this point told that the accounts given would provide a more detailed semi-structured following up interview based on what they, and other participants, had told me. Despite anticipating there would be some attrition, participants stated they were happy to take part. In some cases, it appeared that participants felt valued, as not only was their experiences being listened to but would be of enough significance to elicit further exploration.

The method was successful with some surprising disclosures from participants being made in follow-up interviews that had not at all been alluded to in the initial interview. I believe that this was due in part to the trust and rapport that had been built in the initial interview, and also the participants knowing what to expect based on their experience from the initial interview (Carverhill, 2002). Participants were able to give accounts of if or how their personal circumstances or feelings had changed since we last had contact, this provided an interesting insight to processes of adjustment and difference in their time since the bereavement of their care receiver.

Additionally, the use of serial interviews allowed for participants to reflect upon their experience of providing care in the interim period and add to any particular parts of their initial narrative that they felt they had neglected. This proved to be an empowering aspect of the serial interview method, which strengthened the claim of validity of their narrative and experiences.

3.4.5.2 Joint Interviews

Whilst the intention of the research was to interview individuals who had provided care in an individual one-to-one interview, there were a number of occasions where another family member or partner became involved in the interview. As interviews were carried out in the participants' home, often their family members and activities would be carrying on whilst the interview took place, and on several occasions, someone would join the interview and give their views and experience.

The term "joint interviews" refers to interviews that involve more than one participant (Sakellariou, Boniface and Brown, 2013; Polak and Green, 2016). Some suggest that this unintentional inclusion of a third party does not constitute a "joint interview" (Seale *et al.*, 2008), as it was not a method which was actively sought. However, as there is no agreed upon term for unintentional joint interviews, they shall be referred to here as such to aid exploration of the advantages and limitations of such occurrences.

A disadvantage that has been noted of joint interviews is that the presence of a third party may lead participants to alter their responses and could potentially threaten the validity of the data (Kendall *et al.*, 2010). Whilst this is worth noting, it was felt that this was not the case in the instance of this research as there was little evidence of audience effects altering the accounts of the participants interviewed. I would suggest that this was because they were close family members and often knowledgeable of the person, and the events that they would be disclosing.

The value of joint interviews is dependent on the research topic and the relationship between those being interviewed. The experience of illness is often a shared experience between the ill person and their caregiver(s) and family. This intersubjective experience can have profound effects on the

nature of the relationships in terms of responsibilities, control (or lack thereof), and personal identity, which other family members/spouses may be able to add their interpretation to (Sakellariou, Boniface and Brown, 2013). In the case of this research, it is thought that whilst a third party may not have been able to actively add throughout a purposeful joint interview, the contribution they did make, albeit unintentionally, sought to provide further clarification and insight into the accounts and experiences of the main participant. Often with the presence of an additional family member/partner, the participant was able to actively corroborate various aspects of the account that they had given so far. This may have given additional detail that might not have otherwise been obtained (Seale *et al.*, 2008; Sakellariou, Boniface and Brown, 2013).

3.4.6 Fieldnotes

A fieldwork diary was kept in order to capture additional details of interviews such as venue, context and any other relevant information in order to aid analysis. This is an activity that is strongly recommended by those who have conducted qualitative and ethnographic work in the area of death, dying and bereavement, such as Howarth (2007a). This is due to the area often being new and novel to the researcher and helps capture the change in one's own experience and response to aspects of death over the time of fieldwork.

3.4.7 Photography

As the fieldwork progressed, it became clear that it would be desirable to capture some visual evidence. Participants in interviews were happy to and active in sharing and letting me see and handle items that were significant to them either from their time caring (for example, pictures, letters) or in their period of bereavement when they had items to memorialise with (for example, urn jewellery, tattoos, gifts).

An ethical amendment was submitted in order to approve an additional consent form (Appendix 8) for those to sign that I discussed prior to taking a photograph. Pictures are included in Chapter 6 and aim to give an insight that the written description would have struggled to convey.

3.4.8 Research Ethics Approval

Many of the issues pertaining to the ethical considerations of this research and recruitment process have been highlighted above. However, it is important to note that, this fieldwork required and successfully obtained ethical approval and subsequent ethical amendments from the School for Health and Social Care Ethics Committee.

The research is based on what is deemed to be a sensitive topic by many. Research in such a sensitive area is not unprecedented and is indeed much called for (Milne and Lloyd, 2009), but requires careful consideration. Therefore, all precautions and measures have been taken in the design of the fieldwork to ensure that the research is conducted with the safety and best interests of the participants at heart.

3.5 Thematic Coding and Analysis

The accounts of participants were analysed for thematic findings. Data generated from interviews throughout the fieldwork period continually contributed to the formation of emerging themes. As previously referred to, this provided lines of query for subsequent interviews both raised by an individuals' account and also the accounts of others too.

From the fieldwork, there was a substantial amount of audio from the in-depth interviews. These accounts were transcribed and subjected to an emerging thematic analysis prior to any subsequent re-interview. Processing the data in this way allowed the findings to be discussed with participants in the subsequent interviews.

In addition to the audio from the in-depth interviews with carers, there field notes were taken to reflect the thoughts, feelings, surroundings of each interview and were written up on the day of the interview, or the following day where interviews ended late. These helped provide a broader context to the interview themselves and were also subject to thematic analysis.

This helped generate further data around specific areas of interest across different participants – for example, when discussing feelings regarding memorialisation – and also clarifying particular aspects of their accounts – for example, the timeline of events for their care role.

Upon concluding the fieldwork, in-depth analysis occurred. Data was inputted into NVivo, and whilst coding was undertaken on the software programme, it was also done with highlighters, pens and paper too. NVivo was useful as a data storage manager to retrieve pertinent information from a vast amount of data. However, I was always conscious not to treat the software as a tool that would analyse the findings on my behalf (Gibbs, 2007).

Transcripts from interviews were coded in an open manner, with new themes or sub-themes generated as they emerged from the data. Using a thematic analysis technique means that theory and discussion are developed from the data in an iterative way (Bryman, 2012). Open coding (Silverman, 2014) influenced the coding will allow for the data that is collected to be inductively analysed, however, the data was also processed with the themes that were part of the topic guide, and also out of the themes generated in interviews and reflected upon in fieldnotes. The findings produced from this method of research allows for valid and legitimate accounts to be created that will provide robust and transparent claims and contribute to the original argument of this work.

The data was contextualised with field notes from the scoping done with gatekeepers in the earlier part of the research. The findings and accounts from a variety of community-based leaders will provide a deeper understanding of the regional and structural configurations that lie behind the personal accounts of participants lives.

The findings will focus on where there are similarities, differences and important points to understand further. As such, the work will be presented around themes and draw on quotes and excerpts from narrative accounts of participants in line with the thematic analysis of the data.

A range of experiences are represented owing to the nature of the recruitment process. In order to understand and interpret the findings, it is essential to note and provide context, where appropriate to the material, cultural, everyday circumstances. In thinking of these experiences as representing a spectrum of circumstances, this analysis hopes to go beyond an observation of these differences. The constraints or freedoms that

characterise the experiences of those presented here represent an example of the variability of a hitherto little understood phenomenon. Figure 1 gives details of the participants recruited for this research. The information in the table aims to give the reader an insight to not only the individuals whose accounts will be described in subsequent Chapter 4-6, but also a way to assess for oneself the range of experiences and circumstances the sample represents.

The differences in the personal history of participants in the sample are incredibly varied. The lives, circumstances and nature of the end-of-life and bereavement experiences will be described in the following findings chapters. In doing this, it will allow focus on themes that cut across all participants, or highlight parities, with some contextual information to situate the quote or example given.

Quotes are used throughout to highlight the voices and explanations of the participants themselves. Where there is emphasis (usually in bold), it is done to reflect the audible emphasis with which the participant spoke. Wherever possible, the excerpts attempt to reflect the dialect of those speaking, to reflect the real-world and everyday use of language in this part of the North East, along with dialect and colloquialisms. It should be seen as an attempt to bring voice and character to the accounts of the people who took part, who were full of personality and spirit. It is the dialect in which I speak myself, and this too will be reflected in the quotes.

Figure 1: Table of Participant Details

Pseudonym	Approx. Age	Gender	Borough	Ward Deprivation Decile*	Ward Health Deprivation Decile**	Relative Cared For	Approx. Time Since Death (on first visit)	Occupation	No of Times Interviewed
Joy	Early 70s	Female	Middlesbrough	1	1	Husband	4 months	Retired	3
Pamela	Late 40s	Female	Darlington	3	2	Mother	7 months	Unemployed	3
Sandra	Mid 60s	Female	Darlington	6	4	Mother	10 months	Retired	3
Linda	Late 50s	Female	Middlesbrough	10	9	Husband	2 years	School teacher	3
George	Late 50s	Male	Darlington	9	5	Wife	8 months	Professional	1
Debbie	Late 50s	Female	Redcar	3	2	Mother	2 years	Unemployed	2
Natalie	Early 40s	Female	Stockton	1	1	Mother	2 years	Unemployed	2
Sheila	Early 60s	Female	Stockton	1	1	Son	4 years	Support staff at charity	2
Helen	Late 40s	Female	Stockton	1	1	Mother	3 months	Self-employed / Carer	3
Tom	Early 80s	Male	Middlesbrough	6	3	Wife	1 year	Retired school teacher	2
Ken	Late 70s	Male	Middlesbrough	4	2	Wife	7 months	Retired draughtsman	2
Angela	Mid 50s	Female	Middlesbrough	1	1	Mother	9 months	Unemployed	2
Ian	Early 30s	Male	Redcar	1	1	Uncle	3 months	Unemployed	1

3.5.1 Reflections and Reflexivity

Bourdieu and Wacquant (1992) make a case for the importance of reflexivity and the awareness of the influence of researcher in empirical sociological research. The decisions regarding research design, recruitment, interviewing, and analysis are all taken primarily by me as the researcher. Therefore, my position within the research needs to be clear and accounted for. Not in order that this position can be ameliorated or dismissed, but rather to see the bounds of the reciprocal process between researcher and researched (Dean, 2017).

In order to carry out a meaningful exploration of the issues that goes beyond the observed accounts and analysis of an objective researcher, it is vital to note my potential impact upon those I interviewed. By virtue of the focus of the research, I interviewed people who are different from myself and their perception of me may have affected what they disclosed and how they chose to disclose it.

Whilst I would probably identify most closely with a working-class set of characteristics and values, and also come from and reside within the Teesside, the fact that I am a young female PhD research student from a university will establish a tacit power dynamic between myself and the participant. I was cognisant of this fact, and I feel that my experience of both research, and my non-academic experience, gave me a good background. Prior to undertaking the PhD, I spent several years as a Research Assistant and then as an embedded researcher undertaking a Knowledge Transfer Partnership. These experiences gave me a professional understanding of how to establish rapport. However, the topic of this research was highly sensitive. I also drew upon my experience of working with charities with those in difficult circumstances. I continue to be a Trustee of a local charity whose aim is to challenge poverty at all levels and works with those struggling to campaign at a national level for change, and an individual level to appeal and alleviate the sharpest edges of poverty. I felt that taken together, my experience meant I was well suited for the proposed fieldwork.

However, I had no direct experience in talking with people who are bereaved. This is something I have reflected on since, and I feel there may have been just cause for training around Mental Health First Aid, or basic training around bereavement counselling issues. This would not be to imbibe or implement the framework or discourse these initiatives use, but rather have given me the skills to identify if any participants were showing signs that they required signposting for professional support.

Yet these individuals were letting me into their home a relative stranger. Someone with whom they had only had limited contact with on the phone and were also agreeing to share intimate details of their lives with. They asked me questions about my life and my life experiences. Sometimes this would be directly related to the issue they were discussing, such as, had I ever seen anyone take their final breath, or had I lost anyone close to me. Other times it would be about my life; family circumstances, relationship status, interests, political opinions. I was always honest. I felt strongly that if the people whom I interviewed were generous enough to share deeply emotional and painful aspects of their lives with me that in turn, I should be willing to share openly with them details of my own life.

I would argue that, in being open, participants were able to judge for themselves my positionality.

Leaving the field was therefore challenging. It was acknowledged early on in the design of the research that this might be a potentially tricky aspect. In doing multiple interviews, and sharing such personal accounts, participants – and myself as a researcher – I may become attached. It was difficult. A few participants said that they would miss our interactions. This was challenging to hear, yet I had to remind myself that I was not a counsellor or a friend. However, I had spent a lot of time with these individuals, and it was very difficult not to feel attached or concerned about them. I make no bones that I will continue to think about and wonder how these participants are getting on, for a very long time to come.

3.6 Conclusion

This research was underpinned by a constructionist understanding of the world, and was inspired by a narrative feminist epistemological approach. Scoping meetings with local organisations helped identify gatekeepers who were vital in aiding recruitment of 13 people to participate. Semi-structured interviews allowed control of the time and space to participants, in order that they were best able to narrate their own experiences.

A total of 29 interviews were conducted, as participants were invited to participate in serial or re-interviews. This allowed for considered reflection, emerging data analysis and then specific and relevant follow-up questions in subsequent interviews. A low rate of attrition highlighted the success of this research design. Thematic analysis was conducted and form the basis of the following findings Chapters Four, Five and Six.

Chapter 4: Adjustment to Loss and Complicating Factors

4.1 Introduction

The research undertaken aimed to discover how bereaved carers from a range of socio-economic backgrounds experienced both the end-of-life of a loved one and their subsequent grief post-death.

This chapter aims to explore how participants discussed their experiences, the circumstances in which they lived and the relationships they had and what arose as a result. In describing and sharing detailed accounts of their caring role, the death of their family member, and their subsequent bereavement, their narratives also described many more issues. This chapter aims to highlight how individual, familial, and societal issues all intersected in ways that were inescapable and intractable.

In exploring these issues this chapter will be structured and illustrate the following; firstly, some of the common experiences of participants will be outlined. These pertained to their individual experience of being a carer and/or providing care, and their experience of loss and grief.

Following this the chapter will then focus on the familial issues where participants were explicit about having discord and the attempt to share responsibility within the wider family unit, which could cause (or add to) tense relations. Additionally, this section will describe the experiences of participants who found that the death of their family member could lead to a family dispute, and where (if rarely) these discrepancies were resolved.

The chapter will then move on to describe some of the issues that whilst described as being personal to themselves and the members of their family, are very much examples of wider societal issues. This aims to illustrate the difficulties faced by participants when providing care and/or attempting to grieve the loss of their family member(s). Often these issues were not explicitly asked about by myself as part of the interview, but in describing their circumstances were aspects and details that they could not leave out given their impact and shaping of their lives. Additionally, this section will also

describe some of the financial constraints within which participants were trying to navigate or adjust to.

Finally, this chapter will reflect briefly on absence. The participants included in this research represented a range of neighbourhoods and socio-economic circumstances. It was notable that those that tended to be from relatively affluent backgrounds did not report similar difficulties.

4.2 Individual Experience

4.2.1 Caring at the End-of-Life

All participants selected had provided care and had experienced the end-of-life and death of their loved one. All participants in this research had care responsibilities for the person whom they lost. The label or term “carer” was not always one that participants readily identified with (in fact, this led to changes in the wording of recruitment materials, as is discussed in the methodology chapter).

I never once, as I say, considered meself to be a carer, I cared, but when it's somebody who yer love, you do it automatically. (Linda)

The term “carer” has particular connotations in a British context. With regard to the carer, it is often seen to involve a great deal of physical labour, organisation, and responsibility. Yet many organisations have noted the difficulty in carers acknowledging their role or being identified for the support they may require and be entitled to (Macmillan, 2012; Buckner and Yeandle, 2015). Some participants (Ian, Linda, George, Sheila, Ken) either did not use the term at all, felt it didn't apply to them or saw the care role as being more complicated and attributable to more than one individual in their situation. This could have financial repercussions as will be explored later in this chapter.

For those who did use the term carer or described their responsibilities as care work, it was not always immediately apparent or identifiable where being a “carer” started. In conversation with her husband, Stan, Mary noted the

change in the attitude of her family to the care of her mother, once she had moved her mother into her home:

Stan: *Mind, they didn't do as much as they shoulda done.*

Mary: *Well, no, cause it made their lives easier, didn't it, Darling?*

Stan: *Yea.*

Mary: *Whereas, when she was on her own, they all had to take turns to visit, when she came here it was like, "Oh, she's alright, she's got care 24/7".*

Stan: *24/7.*

The caring responsibilities assumed by participants differed. One of the factors for this was the types of diseases, illness trajectories, or deaths they witnessed varied. Frequently, due to several factors (e.g. disease prevalence in society, access to sample populations), the sociology of death, dying and bereavement has focused primarily on people with cancer (Exley, 2004). This research took a deliberative approach to understand this as a wider phenomenon. The participants recruited in this research had experienced, in addition to cancer, aneurism, heart failure, dementia, seizure, chronic obstructive pulmonary disease (COPD) and general frailty.

In line with other research on end-of-life trajectories that were a result of cancer, those participants' relatives suffering from cancer in this sample also appeared to have a structured palliative care pathway with fairly clear and predictable places to access support. Ken cared for his wife and had unproblematic access to reliable end of life care.

By and large, I would say the care and help and assistance we got was excellent. (Ken)

Participants caring for those with non-cancer illnesses, however, found this to be less predictable. Support for differing diseases is markedly different. Several factors contribute to this, including predictability of illness trajectory, the volume of charitable funding available, access to palliative care, difficulty

with reliable prognoses. Having cared for her husband, who had cancer, Linda compared the recognition that cancer had in the public conscious.

Myself: Do you think there's a difference?

Linda: Yea, I think cancer's more high profile.

Debbie's mother, for example, had COPD for many years, an unpredictable disease. However, she noted that despite asking, she was not made aware of when her mother finally required palliative care.

It is important to note this point here, as these trajectories arguably have an impact on subsequent bereavement. However, some of these issues will be discussed further in the chapter on interactions with healthcare professionals and other organisations (such as charities).

4.2.2 Multifaceted Loss: Love, Care and Security

4.2.2.1 Loss of a Loved One

The death of a family member, spouse, or loved one, and interview participants' care role preceding that, provided the unifying circumstances for all in this research. In experiencing a death, even one that is anticipated, the individual and his/her family enter a new state. The onset of a period of grief or bereavement is inevitable.

Yet there is no inevitability with regards to the conditions, consequences or manner in which death and subsequent bereavement are experienced, the range of circumstances and experience is multifarious. All participants discussed how their loss gave rise to a profound change in their life and circumstances.

You just think "Why? What is going on?". (Angela)

Angela was not alone in questioning the new situation she found herself in. The loss of a close loved family member has consequences for the individual and their immediate family and friends. In certain respects, this is a shared experience, a shared loss. For Ken that meant sharing the loss of tradition with his immediate family.

*She loved to get all the family together, and fortunately that dining table there does extend and we can get 15 around it, and we **did** get 15 around it two or three times a year. They all used to come here for Christmas, so this Christmas is gonna be a bit tricky. (Ken)*

However, for the participants of this research, loss of the loved one was not the only way in which they experienced a bereavement.

4.2.2.2 Loss of Care Role, Ritual and Routine

For participants such as Mary, and also George, Pamela, Debbie, Natalie and Angela, the period for which they provided care was substantial. Each provided care over a number of years, some over a decade. The loss of the intimate relationship when the death occurred, despite in many cases being anticipated, left a sense of dismay.

She was my life for seven years, you know what I mean, all of a sudden it's like "What do I do?". (Pamela)

The instantaneous change for some participants highlighted not only the loss of a family member but a profound change in identity.

The day she died I lost my mother, my best friend and my job all in the same day. (Angela)

The sometimes slow and cumulative way in which the responsibilities and labour of the caring role increased meant the adaptive process by which they became normalised as part of a day-to-day routine, was shattered by the abrupt ending that death brings. In becoming a bereaved carer, they entered a liminal state (Olson, 2014). No longer in their pre-existing role as a carer, but yet to transition and adapt to their new circumstances, the bereaved experienced a period of ambiguity.

For some, immediate commitments filled the gap; care responsibilities for another family member (Pamela, Helen and Angela) or a return to work (George). Other participants struggled to know what to do in their new found circumstances and took longer to reorient their future trajectories without their care role.

Natalie and Debbie demonstrated this period of uncertainty was, what some might consider, to be prolonged and despite their care role ending and their family member (both their mother) having been deceased for over two years, neither had fully decided how to proceed in terms of their day-to-day lives.

Natalie: I still don't know what I want to do with myself, I just didn't know what to do, cause at first I was gonna go into caring, because again that something that – I always wanted to be a nurse, but life took me in a different direction and then I said [...] “No, I don't wanna be – I'm gonna become a carer” and work myself up from there, and I've been and talking to people who are working in nursing homes and I've thought “No, it's not for me, because I want to care” I don't want to be –

Myself: Just the running about, which is what it ends up being, doesn't it?

Natalie: Yea, making the fat man's pockets fatter and the elderly are sat in a chair, and it's not what I want to do, but I want to give care to somebody, I want to make somebody feel better.

Debbie similarly wanted to continue caring and was considering doing voluntary work befriending elderly people, but had reservations of potential bereavements.

As previously stated, for some participants there was no time to step back or orient themselves as the demands of caring for other family members (parents, grandchildren), or working immediately were required attention and attendance. This will become clear in following sections and chapters.

Not only did the loss have a predictable emotional effect, but it often had a pragmatic consequence also. Changes in living circumstances were reported widely across all participants. The death of her husband meant that for Linda her home had become profoundly different.

I'm now alone in a house that was a family home, and it's not now. (Linda)

While it may seem evident that the death of a close family member (spouse, parent, child), for whom care was being provided, would change the makeup of a household, this issue was keenly felt. Mary described the lifecycle of her household:

It was like, y'know, both children grew up, got married and left, there was just Stan and I, then Mum come to live with us, and our life revolved around her, and then when she passed, we were like, absolutely lost. (Mary)

The change to daily routine and ritual could be difficult to adapt to.

It's funny how the death of Eric is almost in the past now cause other things have taken over. But still missing the life we were gonna have together. (Linda)

Despite these differences, and regardless of the necessity to pick up immediate responsibilities, there was frequently a period referenced in which there was disorientation. The reference to this attempt to relocate a sense of self was mentioned by all and emerged as a central feature of grief.

4.2.3 “Doing Grief”

In the data, grief did not emerge as a linear or mechanistic process through which an individual must systematically work. The responses were complex and diverse, reflecting the range of individuals, their lives, and their emotional responses. Traditional models of grief unwittingly create a prescriptive model of ‘appropriate’ grief, and a trajectory for ‘recovery’. Given the accounts outlined, this can be seen to be an exclusionary outcome that does not account or make space for difference.

For some participants, their grief did not manifest in a way that they perceived to be in line with friends and family, or society more widely.

But people say go to grief counselling n'that, I think you just have to get on with it don't yer? (Mary)

Accounts suggested that some options may not be relevant to all. The idea of talking therapy did not appeal to all. Mary found medication (to aid sleep) aided with some of the most challenging aspects of her bereavement. Family and friends can suggest therapy when they feel that it might be necessary.

Linda noted a family member:

Said "Do you not think you need counselling?", "No, cause I was just grieving", [...] I'd always been the strong person and then all of a sudden I was the one who was grief stricken, and I was behaving in ways that the kids hadn't been aware of – not hadn't been aware of, but never experienced me being like that, the strong one all of a sudden is not wanting to go out. (Linda)

It would appear that in describing herself as "just grieving" Linda rejects the implication that her emotional state should be seen as any other than a natural reaction to the loss of her spouse. In doing so, she rejects the medicalised view of bereavement.

Even where some attempted talking therapies, it did not always go well. Pamela sought out bereavement counselling on two occasions. The first time she did not "like" the counsellor; she felt that the reception was cold and she struggled to 'open up'. She did not attend all of the booked sessions. However, some time after, she was still finding her grief to be overwhelming and affecting her everyday life. She was referred a second time and got the help that improved the most debilitating aspects of her grief. Pamela described how a friendlier, warmer and more understanding counsellor was able to help her deal with the anger she felt towards others that had kept her from leaving the house on some days.

In addition, inadequate funding and high demand meant that getting access to talking therapies could be challenging. Helen experienced suicidal thoughts after the death of her father and sought help from a local bereavement counselling service.

They've got about a 6 or 7 week waiting list. I thought "I'll've topped myself before got in there". (Helen)

Participants Helen and Joy found support outside of their family while eschewing medical intervention by accessing support groups for carers. For Helen, her care role had continued so she was able to reach others in a similar position, and found that this challenged the feeling of isolation in her grief. Joy did not continue to be a carer. However, the local organisation who referred her said they were happy for her to continue to attend the carers' support group. The organisation was aware that Joy did not have any family based locally and might become isolated as she was in her 70s with limited mobility. This allowed her to make friends.

It's just nice, y'know. It gives me sommat else to think about, y'know. (Joy)

These social connections and the potential to form new bonds in light of a loss were seen to be important by many participants. In managing and mediating their fluctuating grief and reorienting their identity. In a period of liminality these opportunities to make new, or continue older social bonds could be a crucial way to mitigate some of the most acute aspects of loss.

Yet, at the time of scoping for the research, discussions with carers' organisations based in Teesside highlighted that services or support for bereaved carers was simply not available. It was suggested that this was due to how their work was commissioned by the local authority, who did not deem it a priority and were faced with ever tightening budgets given the austerity imposed by central government.

Responses to and navigating grief will be further explored in the chapter 6. Here it has been shown how when faced with grief the initial response of some individual participants has been diverse and the formal therapeutic model has not always felt appropriate or been wholly successful for all.

4.3 Familial Relations and Networks

Often crisis of health and illness can place an immediate need for assistance and intervention from the surrounding family. These relationships can be put under stress when care and treatment have to be negotiated. All participants

discussed this to a greater or lesser degree with a particular theme emerging of the difficulties these relationships caused.

For some, it can also be the case that those from the wider network of friends and neighbours may be involved in providing support to the participant, albeit to a lesser intensity of that of family members. Some of the experiences will be highlighted here where the social expectations of the wider support either exceeded or fell short of anticipated expectations.

4.3.1 Conflict, Difficulties and Distance

The interviews aimed to understand the social context within which participants experienced their care role and subsequent grief and bereavement. Across all accounts either due to prompting, or arising naturally out of the accounts of their experience, participants referenced the support networks they were situated within. The majority of participants noted that there were differences of opinion within the family. These differences were to a greater or lesser degree. Some may have been small ways in which their opinions or expectations differed, or ranged through to conflict requiring mediation or legal involvement. They also presented at different stages in relation to their experience of end-of-life caregiving, death, and bereavement. This section shall describe some of the differences.

4.3.1.1 Pre-existing Issues

For some participants, the tensions within the family pre-dated the onset of illness, care responsibilities, and subsequent death of the person cared for.

Describing his family, Ian suggested that he had little in common with his family which helped to explain how and why his relationship with his uncle, with whom he lived and cared for, was closer. I had asked if he had a big family in relation to him discussing how his care relationship with his Uncle was very isolated.

We have quite a big family but we're not – half of the family doesn't talk [...] No one's a saint in this world, far from it, but there's a lot of people in my family that – without trying to judge – I wouldn't give 'em the time of day. Not that I'm anything special, I'm not, but I wouldn't have my kids around

'em cause they're a bad influence. I mean I've made mistakes, I've been to prison, so I can't say the sun shines out my backside, it doesn't. But at the end of the day yer still look at what you've done in life and how they go about things, and it's like "No, I don't rob old grannies". (Ian)

It was important for Ian to keep a distance from his wider family due to the potential for disagreement or protecting his children from being led astray. In terms of providing care to his Uncle, he did not reach out to anyone else. He invited his Dad to visit days before Nigel's death:

Dad was like in shock because he hadn't seen him for so long, errm, n'then when we left, I said "Now d'yer know why I've had a drink?" Cause having two people there at once just a lot for me. (Ian)

The stress of caring for someone who is in the final stages of illness made Ian communicate to his father, yet even the reality of this when in the room proved challenging. Inviting family members with whom there have been previous difficulties was seen as something that *should* be done. An underlying imperative based on the moral implications of a family member being on their deathbed.

This moral imperative to allow extended family members into the end-of-life setting despite pre-existing conflict was found elsewhere. The relationship between Sheila and her sister had been difficult for many years, with limited contact. Despite living very near and being civil when they did see one another the interactions could become heated and hostile. This antagonism did not abate even when her sister came to the house immediately upon hearing that Carl had died.

I don't know why, but it seemed to be, y'know, push me out [Sighs] n'I dunno why, but I felt I could not say anything because my son was dying, my son was – but everybody else was having the say, y'know [...] When Carl had died n'they come round, I mean, he said he didn't want anyone there, he didn't want anyone looking at him [...] As [if] they

were at a pantomime. He didn't want that, but I couldn't stop that, y'know. So anyway, even she come round and I was sat on the chair, I mean, honestly I didn't cry, I didn't cry, I couldn't cry, I was frightened to cry, cause I had no right, der yer know what I mean? N'she come in, n'she just, she looked at him, n'she looked at me [Raised voice] "D'yer know, we all loved him, not just you, we all loved him", I said [Very quiet voice] "I know yer's did". I mean, for me, I wanted to stab her, I wanted to knock her head off but keep calm, Sheila, keep the peace. (Sheila)

In these highly emotionally charged situations, there appears to be a need to balance the family dynamics that can be very difficult if the relationships between the family members are already fraught. The consequences of these difficult situations can be seen in Sheila's descriptions of how it impacted her ability to grieve, in that she didn't feel she had the right and space to grieve due to the scrutiny of her sister.

4.3.1.2 Care Related

For some participants, the challenges posed by care responsibilities caused or provoked conflict within the family. When it came to providing care for her mother, Angela went to great lengths to accommodate her. Having had an extension built onto her home and having her mother live with her and her husband full time, Angela described her relationship with her only sister, a third sibling having died under unexpected and tragic circumstances.

We had a little bit of a disagreement on Mam's care. She was working, but obviously, between the two of us our priorities were very different, she would rather be at work and I used to say "This is our Mam" [...] So we had a little bit of a dispute and the outcome wasn't very good. (Angela)

In order to facilitate a holiday for herself and her husband Angela approached her sister to help with respite care. Returning from a week holiday with her husband, in which her sister gave respite care, Angela described the encounter:

When I come back, she said “Our Mam’s been terrible while you’ve been away”, she said “So I think if you and Greg [Angela’s husband] want to go away in the future you’ll have to look for residential care for her”, so I was just dumbfound, I was just shocked [...] She just couldn’t do it. And I did do the residential care [Begins to cry] but it killed me. But I think, she will never understand how that made me feel. (Angela)

In providing care Angela had noted that she and her sister had different values in their lives, and in not being able to understand or come to an amicable arrangement where both siblings were satisfied it led to their not speaking until the death of their mother over four years later. Different expectations of the share of care and who takes responsibility within families were not uncommon amongst participants accounts.

While caring for her terminally ill husband, Linda also had to share care responsibilities with her brother for their parents. Linda described a conversation regarding the care that contributed to a prolonged fallout between her and her only sibling.

Linda: Me brother likes to throw his dummy out, n’he turned to me and says “Well, you can look after Mum and Dad’s finances” I said “That’s great, I’m the one who does all the care level”, n’I said “N’as if I haven’t got enough on, David’s starting chemo”. N’yer what he turned to me and said? “I’ve been waiting for you to play the chemo card” [...]

Myself: What a thing to say.

Linda: “I was wondering when you’d play the chemo card”. My husband was dying. The chemo was only gonna give him a bit more time.

The expectations within families, and how to share responsibility for care, could lead to tensions that then release in damaging ways. This was the case for Linda, who clearly was very affected by this comment even years after the event.

For Helen attempting to manage the care of both her parents under the same roof and also the contributions to care from her siblings proved to be very difficult.

When my Dad came home [from hospital], she [sister] didn't stay very often but [...] She was there a bit at the beginning, but then she – all the time it was like "I can't do this, I can't do that", I said "Take yourself out of the equation, n'come and visit our Mam [and Dad] as a daughter like you used to once in a blue moon", so that was it, she did, but she hardly [came]. (Helen)

Assuming responsibility and actively absolving her sister of similar commitments allowed Helen the opportunity to avoid some of the discord that was arising as a result of apportioning care. While it may not have worked in the long-term (as will be discussed), it gave Helen the ability to have guardianship of her ill parents without questioning.

4.3.1.3 Post Death

While to a lesser or greater extent, all families anticipated the loss of their loved one, this did not always mean that there had been an expectation of the consequences of the loss for the family interaction. The dynamic by which siblings and relatives may have previously behaved toward one another may have been altered, intensified or concluded by the death.

The nature of the interviews with bereaved carers often meant that the person who was interviewed was the member of the family who had assumed the majority of the responsibility for the care pre-death. This could effect how they were perceived or the place they had within the family post-death. While it is important to be mindful of this, the accounts given were extremely candid and with proximity to the events.

For Pamela, she was often still seen as the crux of her family even during the tensions after the death. In trying to sell the family home left to the four siblings after the death of both her parents, Pamela's family had struggled to trust one another. Before the death of their mother Pamela's sister, June, had altered the deeds of the house to include the names of all siblings (two

sisters and two brothers) as their brother was living in the house. Pamela stated when this was initially done she was surprised as she never felt her brother, Anthony, would be resistant when the time came to selling the house and distributing the assets equitably. Yet after the death of both their parents, it became tense.

Myself: So has that caused any friction or anything?

Pamela: So, there's Anthony [oldest brother] who lives round the house, June [sister] who came back after the forces, there's me and there's John, the baby. Anthony doesn't talk to June, Ben [youngest brother] n'Anthony don't talk, so when there's any disagreements or anything, they all come to me, it's all on my shoulders to go n'tell them to tell them. N'he's [husband] said to them all now, he said "Grow up, n'get some balls", he said "Stop putting everything on her back", he said "I've had enough of it", he said "If yer wanna scream n'fight, scream n'fight". So if there's a little comment they don't say it round Roy [husband], they still say "Well, pass this message", but they don't go anywhere near him cause he tells 'em. [...] So it just causes atmosphere all the time, doesn't it? Y'know, them two won't talk, them two don't talk so I'm stuck in the middle, n'if they both come here at the same time – ooh – one goes out there, n'I'm talking to one in here and – aww [Puts her head in her hands].

Assuming the responsibility for the siblings working out their disagreements led to pressure not only on Pamela, but on her husband who grew frustrated with the circumstances.

For Natalie assuming the responsibility for the care led to very different circumstances post-death. In providing one-to-one care for her mother over several years, both Natalie and her mother's relationship with her two brothers and sister became somewhat distant. Due to her close relationship, and giving up her job and home to care for her mother, Natalie was placed on the deeds to the house owned her mother and late father. In the immediate

aftermath of the death of her mother, significant challenges arose for Natalie when household items and her mother's jewellery went missing from her home when she was staying with her partner.

Natalie: Yea, a lot of the stuff was what I'd bought when I was living in the flat and she'd [sister] just helped herself. So the lads [two brothers] came and there was loads of trouble and they made her go and get the jewellery, cause she's only took stuff that was worth something. So that they made her go get all of the jewellery and then, um, there was loads of trouble over it and then, um, I came back here [partners home] then we went back a couple of days later and someone had been in again, so for all I'd taken my keys off her she'd obviously had another set cut, so I changed all the locks and said "I'm not having it", so I called the police at that point, so it became a police matter, but because it is – the house was half Mum's it's got to be a civil matter, so they said "She's got obviously some claim" but not to anything of mine. So that's what it all became about, this happened 2 weeks after losing Mum. So it was.

Myself: Oh my gosh. And so that's still ongoing now?

Natalie: Yea, we sold the house, which I felt pressured into doing, but they were just watching me constantly, I said "You couldn't move around the house", it was really uncomfortable in the end.

There were similarities in the accounts of Natalie and Pamela, both described an increase in familial communication over the period in which I interviewed them. Yet for Natalie she described how she became progressively marginalised from her siblings. Whereas for Pamela she was viewed as a central point of communication between her siblings.

Whilst not all accounts may have seen family conflict escalate to legal proceedings, it was notable that the overwhelming majority of participants'

accounts reflected difficulties at end-of-life or the subsequent period of bereavement, with their family relationships. In the case of Tom he comfortably reflected on the relationship shared by his family, in particular his three adult children and stated:

I couldn't wish for three better children. And they get on well together. (Tom)

He talked of how this made decisions around care, memorialisation and his bereavement much easier. Ken discussed similar easy relations within his family, and went on to note the geographical proximity in which his adult children lived meant that now he was bereaved and on his own their frequent visits meant he felt less alone. Ken also highlighted how important the role of his family was in the end-of-life period for his wife.

We have had the benefit of that immediate support. (Ken)

The absence of familial tensions and conflict, as described by Tom and Ken as having harmonious family dynamics was a rare one across the accounts of this research. More common was for the difficulties and upset of pre-existing issues, care related decision-making, and managing and coping with loss to create or entrenched tensions and conflict within a family.

4.3.2 Resolution

The tensions and difficulties described above by participants gives insight into the aspects of care roles, and how grief and bereavement can be complicated by the relationships with siblings and family members. Participants often hoped to resolve the tensions within their family, yet the end goal was not the same for all. Natalie described how she would be happy to no longer have any contact with her siblings once the legal case against her sister had been resolved.

Natalie: We should've all pulled together [...] Don't get me wrong [...] I am now a very strong person which again I've got Mum to thank for that, I don't need any of them, but you just think – but it's poor Mum now, cause it'd kill her to think that we were all estranged now. It would break her heart.

Myself: *Maybe in the future you might get to a point where-?*

Natalie: *I wouldn't now – I wouldn't.*

This resolute approach was not available to others. After the death of her father Helen continued to provide care for her mother suffering from dementia. Helen reflected that whilst she had hoped that obtaining power of attorney for her mother would mean that she would no longer have to consult or be restricted by the intervention of her sister, however this had not been the case.

Helen: *I'm having massive trouble with my sister and my brother – oh, you wouldn't believe, it's like one thing after another just, so my head's been totally in the shed. I went through one point where I just balled my eyes out all the time, I couldn't even talk to nobody, whereas now I've got a bit beyond that, but I'm like – still have my meltdown days. But, so what we're gonna do, I've had to – even though I've got power of attorney and power of health, I keep getting told it's not worth the paper it's written on.*

Myself: *Really?*

Helen: *Honestly, the social worker because my sister's questioning everything, even though I'm doing everything in our Mam's best interest.*

The intervention of social services to help to mediate the situation between Helen and her siblings to provide care highlighted how very far the relationship had broken down, and neither party were prepared to relinquish their stance.

The struggles to reconcile weighed heavy for others too. Angela continued to have a relationship with some family members and had tried to make peace with herself for the situation she was in after the death of her mother. She found it was difficult to reconcile with her sister.

I still have that relationship with them [niece and nephew], which I'm glad of and I still have the relationship with her [sister] grandchildren, they're still coming. So it's just the actual fact that it's me and her, y'know. But I just thought, when you've been hurt like that it's hard. I mean I know it's all about forgiving and stuff and everything else and I do tell myself that. (Angela)

Angela never did resolve the upset she had towards her sister, but had said in the final interview that she would be civil if and when circumstance dictated that they communicate with one another.

By the final interview, Pamela she hoped that the sale of the family home would mean that even if her siblings did not resolve their differences, she would no longer be the outlet for their frustrations and the conduit by which messages would be passed from one to another. She would finish talking about the issue with a sigh and: "It'll all get there in the end". There may be hope for some participants of resolving the tensions within the family, but due to the nature of disputes and their ties to care or death, it can complicate already heightened emotions.

4.3.3 Support

Where there was conflict within a family there could be a great deal of focus from the participants. This may have been with one or more family members, yet rarely their entire extended family also. When questioned about support that they received, participants referenced family members first and foremost as being points of assistance and strength.

The make-up of families was varied and did not always reflect notions the "traditional" family unit. In the instance of George caring for his wife, Judith, was done, in addition to himself, by his daughter (Judith's step daughter). For Judith the majority of her care was done by her step family rather than her biological grown up children. George described how they had not been able or willing to manage and help with her diagnosis of early onset dementia.

Margaret was my second wife, she had two children of her own who basically deserted her when [pauses to indicate at the onset of illness]. (George)

Despite this George was happy that there was support and went on to say:

So it was fortunate that we all rallied around and then Margaret's eldest sister, she was good, but she lives up at Stanley, she used to come down regular. (George)

Mediating and brokering support at times of illness and decline was important throughout many of the families of participants I spoke to and this was easier for some than others.

Debbie discussed how after the death of her mother her life changed and in that period of adjustment I asked about did she feel she had the support of her family:

Certainly with my sister, but obviously my sister lives in Australia so it would just really be phonecalls [...] We're a small family. I suppose only in little ways that, y'know, as a little time went by you'd have a – you'd share a memory with them, you know, something happy, not about what happened at the time [of death], yea, you'd have your little "Eee, do you remember when this and that". (Debbie)

Regardless of distance or family size for Debbie it was important to manage her grief by focusing and remembering positive times. The emotional support was of great importance due to the change in her life, having previously been a full-time carer for her mother, that she now faced in light of her mother's death. The support of family was mentioned by many participants, even those who discussed there being conflict with some family members, would stated that they were supported by other family members.

For Ken the proximity of his family was a source of support that he reflected upon in the bereavement of the loss of his wife.

One hears so much about people having all sorts of family problems [...] And we don't seem to have that. We just all seem to get on together which is very comforting in itself so perhaps that's something that we've got going for us that has helped us all to get over this particular point. (Ken)

This support for Ken was important during Ann's period of illness before for death also. His reflection on others having "family problems" was based on his own interactions with others, but shows how Ken was cognisant of his own relative lack of challenges, and how that had actually helped him and his family in their time of loss and bereavement.

4.4 Societal Issues

Accounts shared by participants often included details of their own lives and the lives of their close family and friends. These stories often necessitated contextual or supplemental information to piece into place the relevance of the story being told. As could be expected with narrative interviewing, this was a common feature to the majority of interviews – there were stories within the story. Yet within the sample of participants, there was a particular concentration of similarities pertaining to chaotic or perceived to be non-traditional lives. Participants described their care responsibilities, or bereavement being preceded, disrupted, or complicated by numerous family, personal or social issues.

While there were similarities in issues across all participants that I interviewed, in terms of their experience of caring and loss, there appeared to be events or issues that added to their difficulties in their lives. It was notable that for some participants, their challenges were numerous and for others they reported relatively stable circumstances. These differences will be explored in this section.

4.4.1 Friends and Neighbours

When asked the majority of participants stated that friends or neighbours did not contribute any notable support or aid during their caring period. The end-of-life period appeared to be a time for personal and familial relations to attempt to unite or share responsibility. In the period of grief that followed

relationships with friends and those in the local community highlighted variance and participants reflected on what the support, or lack thereof, meant to them.

Joy lives in an area of Middlesbrough that is very central, but also characterised by extreme deprivation. She found that after the loss of her husband she was surprised and overwhelmed by the amount of condolences from neighbours in the local area.

It was amazing just how many cards were sent, there were a lot a – well – I've still got them all, err, and of course, everybody went to the funeral – things I didn't expect, y'know. And, errm, they wor all so nice, they wor all so lovely, and as I said, they all said really nice things about him, it was nice, it wor lovely. (Joy)

After the death of her husband, a younger male (in his forties) neighbour who lived alone was saddened by the news and took to visiting Joy once a week to check on her. She was able to call him if she had a fall or needed anything from the shop. Unfortunately, by the final interview she shared that he had been found dead in his flat after suffering a heart attack which left her a little more isolated.

Linda described how she felt that after the death of her husband she was let down by her friends, and when asked if she thought people had avoided her out of their own feelings of discomfort she said no and went onto explain:

But funnily enough, some friends who I thought would really care for me, haven't [...] I mean one of them, I went in the August after Eric died to [a] play with her and even though I phoned her up since. She was the one who we went to [away] with, n'it was all "Right, we'll go across to New York together, we'll come back here together, Linda, n'da-de-da-de-da". N'y'know, "I'll make sure we do loads together, Eric don't worry, we'll make sure she's fine" [...] She's not – n'they weren't happy cause I'd organised the funeral n'they were elsewhere in the country, n'she wanted me to hold the

funeral off, back a bit [...] They haven't bothered with me, but I'm not bothered cause I think in the end you find out the people who are truly – I've got one friend who's always – she comes to see me, she lives in [nearby town] about every 10 days, cause I have isolated meself, quite a bit. But then I think at the same time it proves, I had to find out who I was on my own, but I also think it makes you realise the people who truly do love you. N'they're the people I want to spend me time with. Not the people who at the beginning, y'know, we went [away with] – we allowed them, how I see it, to share our last month's together, n'yet now Eric's not here, I'm immaterial. (Linda)

The expectations that Linda were based on the assertions her friends made during Eric's terminal illness that they would not disregard her once Eric had died. Whilst Linda felt she had learnt something from the experience, it made her careful with sharing her time and emotions in order to "isolate" herself.

Isolation during a period of bereavement may not always be self-imposed. Angela described how people in her local neighbourhood would react to her after the death of her mother:

I used to put the dog on the lead and our Mam used to push her wheelchair and we used to just do it slowly. But we still – obviously a dog has to be walked so yer talk to people n'stuff like that. In the beginning, there were people – which I do know this happened, were sort of like avoiding yer a little bit 'cause the conversation had gone [...] But then when what's happened's happened, at first people were frightened to approach yer 'cause like yer say, they dunno what to say. One girl used to shout "How's Ma? How's Ma?", y'know "She's alright" if I've just nipped out n'I haven't got her with us, 'cause there wasn't many places we went without each other, to be totally truthful. There wasn't. N'now this girl, I

think when she sees me, she can't say that, that thing that started the conversation off, doesn't anymore. (Angela)

Angela went on to describe how some of these exchanges had become less arduous, but the experience had left an impression on her. Participants would refer to the difficulties that they faced when interacting with others during their bereavement due to the concerns of the other party not to upset, offend or bring up a taboo topic, meaning that these interactions could be stilted.

Having lost his wife Ken reflected on the attitudes and contact with others during his grief:

People outside of the family, do seem more inclined to be a little bit circumspect in their attitude in conversation when I see them. But I've always taken that to be a sign of the fact that they're not sure how I'm feeling or reacting or whatever, so they're playing it a bit cool or low-key, y'know, just so as not to engender any bad experiences for me, rather than thinking of how it's affecting them [...] But to be, to be blunt about it there haven't been all that many contacts with people outside of the family [...] People who knew Ruth as a friend, and she had this particular circle of lady friends who had this, err, textile group, I think they – well, they've always been good at remembering to send a card still on her birthday and Christmas cards with the right kinds of expressions, errm I dunno, expressions of what? Comfort is the only word I can use. [...] But I think people do still want to hold back a little bit in anticipation that whatever they say might trigger thoughts that they might not want to see displayed by the bereaved person. (Ken)

Ken described similarly to Angela that conversation could be reserved due to the concern of not wanting to cause undue upset. Yet for Ken, those who did reach out and actively remember his wife, Ruth, on important occasions were welcomed. It appears that there are appropriate ways in which this should be done to “express” a connection that provides “comfort” for the recipient.

This connection with wider networks could be a source of disappointment or a source of comfort. However, there was little that participants could do while attempting to manage their responsibilities, grief and upset, to also engage with assuage others. For some, this was too difficult and so a sense of being let down or isolated could confound already arduous times.

4.4.2 Financial Precarity: Home, Work and Money Worries

Financial constraints could be hard to overcome in times when participants had significant care responsibilities, as their time was taken up by caring. This placed constraint on their ability to undertake paid work. It could mean having to borrow money from friends or family. It was also difficult to navigate and manage things relating to money such as housing, tax, and the significant cost of a funeral in the immediate aftermath of the death, and subsequently into their bereavement.

Many participants had discussed carer's allowance and either had problems accessing carer's allowance or were not eligible. For those who had received carer's allowance, they noted that they had not realised for a long time that either what they were doing would be considered care work, or had not realised that carers' allowance existed. Mary had been in contact with numerous services whom one might expect would have signposted her to potential financial support, given that she had moved her mother into her own home. Despite seeking out information and advice to access financial support Mary was not successful in obtaining carers allowance.

No, they said I wasn't entitled to it because I was over 60 or something? I don't really. (Mary)

Several participants (Pamela, Sheila, Ian and Helen) told life histories that often revolved around many differing jobs, all low-paid, insecure and with periods of unemployment. This experience of precarious employment was often referred to in describing how they came to be at the point of providing care for the deceased. For some they were most conveniently positioned to take up care responsibilities and either move into part-time work, or stop working in order to prioritise caring. However, this was not at no risk or cost as often their jobs were difficult to come by and retain with any longevity.

For some their immediate concern was housing, and associated household bills. Ian cared for and lived with his uncle, Nigel, in a home that Nigel had been renting from a local social housing provider for many years. Upon his death the tenancy of the house became uncertain, with Ian unsure if he would be evicted from his home:

Well I signed the tenancy Tuesday, but about 3 days before that, that's when he said "It's good news you can have it", for that time period, no it was a nightmare, it was just limbo, no one was telling me anything, I had to ring 'em up about 4/5 times. (Ian)

He went on to describe other issues that had arisen with regards to accessing the state social fund for funeral costs. This will be explored in the following chapter due to the nature of dealing with official bodies.

Sheila also reported difficulties in affording the cost of a funeral for her son when he died in his thirties. Deaths of those who are younger were not necessarily expected and therefore did not have the same financial planning that would allow the family to cover the costs of a funeral easily. This could mean that funerals could have difficult financial implications that required resolution by accessing the social security funeral support fund. Sheila described the arrangements for her son's funeral:

His friends paid for everything, his friend were marvellous, I mean, I would've paid for it if I had to. (Sheila)

Sheila had described how some of her son's friends were known to be associated, as had her son at one time been, with criminality. While it was never verbally communicated where the money came from, the tone of the discussion left me feeling that what was being said was that by any means possible they would cover the cost of his funeral and ensure it was a respectable ceremony.

Ian and Sheila were not alone in facing such practical issues associated with low income and poverty. After the sudden death of her husband, Joy found

she faced numerous problems with adjustments to pension payments, rent and council tax.

They nearly had me going round the twist. I said "I just don't know what it is", anyway, finally I got somebody with a bit of sense, and they got it sorted. (Joy)

These issues were often linked to being on a low income necessitating seeking financial support or reporting changes in circumstances. Participants reported feeling frustrated, powerless or overwhelmed by these processes and bureaucracy.

As was discussed in a previous section some participants noted familial problems relating to claims of ownership or inheritance. Particularly for Pamela and Natalie, the pressure to manage the assets left, and sell a familial home was palpable and this pressure was as much from family as it was to provide some financial stability for themselves.

It is important to illustrate here that these issues appeared to be particular to those who were living in comparatively disadvantaged communities, thereby adding cumulative strain to an already stressful and upsetting period of their lives. Some participants (Tom, Linda, Ken) did not discuss any concerns or issues regarding finance or report any such issues causing them stress at a time of bereavement.

4.4.3 Substance Misuse

Several participants described personal or family situations that added challenges when either caring or bereaved in relation to substance misuse. Due to the open nature of the initial interviews with participants in which they were unrestricted in their time and space to narrate their experiences, disclosure of most of the following insights were shared without much prompting.

Helen described difficulties with her husband that had added problems in the period when she was facing the hardest struggle with grief.

I'm sort of a carer for him cause he's a heavy drinker [...] and so obviously it causes a lotta trouble, so I've got dealing with him as well. (Helen)

Throughout multiple interviews, Helen described how having lost her father, for whom she cared, she had to carry on her pre-existing care role for her mother, who had dementia. Managing both the grief and her continuing care role was a challenge; however, this was exacerbated by her husband's drinking problem.

I'm not strong enough to leave my husband, but I feel that if he pushes me too far, I'll have to because I can't cope with him and ma Mam, so I'd rather cope with ma Mam than him. (Helen)

Over the time I interviewed Helen, she still didn't feel like she had been able to grieve properly, in part due to the other aspects of her life, including her husband's alcohol misuse and paranoia. The care responsibilities for her mother meant that while handling the organisation of her father's funeral and affairs, she was almost daily travelling between her own home and that of the site of care.

Issues of substance misuse were mentioned as being part of the lives of other participants also. Both Sheila and Pamela referenced family members who struggled with substance misuse and drug addiction. Often deaths of young people, and in circumstances that reflected the chaotic nature of their lives and surroundings. This could lead to premature death and it was not uncommon for there to be awareness of multiple young people in the local neighbourhood who had died as a result of drugs and/or alcohol.

These deaths were often at a significantly younger age than the national or regional average. One participant frequently referred to the death of her son:

Pamela: I still think I haven't grieved for ma Mam yet, because I'm still, like, with Luke so much.

Myself: How old was he, if you don't mind me asking?

Pamela: 23. *Stupid, stupid drugs. [Tuts] But that's life, innit?*

The consequence of her son's drug use, previous prison sentence, and subsequent suicide was particularly difficult for Pamela to manage. Alongside these events, she was caring for her father, who passed away, and her mother, who also passed away. These multiple bereavements were different from one another, and as such, presented Pamela with complex emotion work (Hochschild, 1983).

Several participants noted that the occurrence of multiple bereavements within the circle of family and close friends had affected their bereavement. For Linda, this was a family that had frequently experienced the tragedy of loss, due to cancer and other diseases. Yet for some other participants, deaths were linked to troubled lives in terms of substance misuse and addiction. By the very nature of the illegality of some substances the effects at the time and the aftereffects were very different due to the negative and stigmatised manner in which drugs are viewed.

4.4.4 Criminality and Incarceration

Criminality was referred to, mainly concerning theft, violence, and this had led in some instances to family members, or the participant themselves, spending time in prison.

Yea, yea, our Carl, he was a bugger, don't get me wrong, he was a bugger, but he was a loveable bugger, y'know what I mean, he was my son, he done what he done, he never pinched off old women, he never burgled houses, he never done owt like that, yes he done shops, ram-raided shops when he was younger, he pinched off the wagons that were parked up, them were the things he done, [...] But he never touched an auld woman, he never touched a kid, he never done anything like that – he was nothing like that, y'know.
(Sheila)

The neighbourhood in which Helen lived was one of the most deprived in the area and had high rates of crime. While trying to grieve the loss of her father and carry out ongoing care responsibilities for her mother, her husband and

son were arrested after violently confronting a suspected drug dealer on the street in which they lived.

The police conducted a raid on her house in order to arrest her husband. The case against her husband and son had the potential of them each facing a prison sentence of two years or more. However, due to the weight of evidence against the drug dealer they were issued caution and the family were advised to continue logging and noting incidence of drug deals being conducted: "Imagine how draining that is on us?" she noted while trying to grieve and care for her mother.

This is what sent me over the top aswell, when he's [husband] being so horrible about my Mam and what 'ave yer, I just think "How much more can I take?" (Helen)

Helen increasingly felt vulnerable in her own home had even installed fireproof letterboxes as a precautionary measure. The competing worries, chaos and caring responsibilities in her life put further strain on her perception of her ability to cope and to grieve.

Ian described how he had spent time in prison for previous criminality, but was trying to stay away from family and friends who could potentially involve him in further criminality.

People I know, they're just not worth bothering with. (Ian)

He had children of his own and so he was keen to keep himself and them away from the worst aspects of his families indiscretions. This was important to him to try and improve himself whilst also dealing with his mental health issues.

4.4.5 Domestic and Sexual Abuse

Participants raised examples of abuse from their past. This reflected childhood sexual abuse, domestic violence towards participants from partners and towards their children. In one case, a participant had experienced sexual abuse as a child from her father. Those who were aware of the problem assumed that her mother must have known and questioned how she subsequently coped while caring for her for so many years.

But, yea, that has a lot to do with how I am. Cause a lot of people, like me sisters, they were abused and they said "Our Mam musta known", and yea she musta known, so they said how did I manage to look after her all that time without resenting her. But I didn't. (Mary)

Throughout the multiple interviews I conducted with Mary it was clear that her experience of parental sexual abuse during her childhood had a lasting impact. It cast a shadow over her, and her sisters, ability to grieve for the loss of their mother. Given that both her father and her mother had since died it seemed to preclude any ability to get justice for the historic abuses.

Domestic abuse also played a part in the reordering of families and Joy explained that the loss of her husband was difficult for her daughters. While he was not the biological father of her daughters due to an acrimonious separation caused by violence towards her, and then subsequently her daughters, they looked upon their stepfather as a Dad. She described the moment she realised her ex-husband had been perpetrating domestic violence on their two daughters.

They're banging on the front door, n'we opened it, it was the two lasses, he'd started lashing out at them when they went in, and hitting them, and I said "How long's this been going?" [...] I said "Now, we're going to your Dad's, I'm tekking yer" n'I said "What we do is, we go in yer Dad's, you two'll go pack yer cases" I said "And then yer coming home with me and that's gonna be the end of it, you're not going back again". And he'd done all sorts to them, and, err, of course he liked drinking, so this is where the money went, rather than the kids. [...] I'm stood there like and he says to me "What've you come for?" I said "I've come here to tell you, yer not touching them girls ever again", I said "Knock somebody else about, but yer not knocking my kids about", I said "I'm telling yer" I said "It's about time" I said "Yer took a look at yourself to see what you're doing and what you've

done, n'what you haven't done", I said "You don't deserve these girls" I said, well, I said "They're coming home with me". (Joy)

From this point Joy and her husband Frank, the girls step-father, raised the children. Joy happily talked of how they saw him as their father. This led to their collective bereavement at the loss of a husband and father being layered with some complexity in that they had lost the father figure that took them from a place of violence, alcoholism and danger.

It is worth noting that references were made by several participants to difficulties with mental health issues experienced by themselves, the deceased person, or other significant family members. People referred to depression, anxiety and agoraphobia, and personality disorders. A bereavement could exacerbate an underlying mental health problem. These are discussed in various aspects of the findings as they often are talked of in relation to other issues.

4.5 Differences and Absences

All of these events were related to the care, death and bereavement the participants had given or experienced. To disentangle the narratives and exclude these important events or issues would be to enact a form of violence upon the participants by silencing or editing their stories. Not all participants in the sample described such experiences. Where there is an absence of participants reflected in this description of findings, it is due to the absence from their accounts. Of those from whom these issues were present reflected those whose lives were characterised by precarity.

It was interesting to note that those from more affluent circumstances within the sample rarely, if ever, noted such inter-relating issues that affected their grief. As previously noted, there was little prompting in initial interviews. Due to the nature of the follow up interviews, there were questions that would have allowed opportunities to share any wider life events that may have had a bearing on their accounts. However, the obstacles that some described (as outlined above), were not reported by those who were more affluent, even when given the same platform and prompting to do so.

There may be a number of ways in which this could be understood. The absence of these issues may suggest that those from more affluent circumstances either withheld such information or incidents. Alternatively, it could suggest that the additional complicating factors outlined here may not have occurred, or occurred with such intensity or frequency, to be noteworthy.

Both potential explanations say something interesting about social class differences. Firstly, in suggesting that those from more affluent backgrounds may withhold information during a series of interviews for which they have consented to take part points to significant differences in the value of privacy. Those who were well educated and had professional occupations may see participation in research as having inherent value but may be unaccustomed to the questioning of a particularly personal nature. For the middle class, it can be argued that the ability to have a secure and private personal life is expected. Despite assurances of confidentiality, it may, therefore, be difficult to share details of personal or family issues to a researcher. The issues outlined above often come with a stigma attached.

However, the alternative explanation may be that those from more secure and affluent backgrounds did not experience issues around alcohol abuse, multiple bereavements, domestic violence, criminality and prison sentences. Statistical evidence of the rates of crime, ill-health and overall deprivation in the areas which these participants lived would suggest that it is the case that those who were more affluent in my sample, were much less likely to encounter the same sorts of concerns. This was not the case for all those participants interviewed. The difficulties and stressors could start from early in their life history and linked in their narratives to many of outcomes and experiences thereafter. The long-term effects of this were evident, as Mary reflected:

I didn't get the best start in life, and I think it was like a lot of – when they say you have low self-esteem, well you do. You know, thinking about things I coulda've done, but I never had the – [sighs] uhh – the courage to do them. (Mary)

The cumulative effect of multiple stressors across the life course has been well documented (Pearlin *et al.*, 2005). More widely the social sciences and health research have noted that the types of stressors outlined above, experienced by the participants, are linked to differences in socio-economic or social class status, for example as Reay (2005) would suggest that these differences are part of a circular process that informs an economy of the psychic realm. The everyday psychic harms of class or the 'hidden injuries' (Sennett and Cobb, 1973) are inscribed onto the working-class and continue to limit and shape their trajectory. This will be discussed as further findings are explored.

4.6 Conclusion

The accounts described here are difficult to hear and read about. To imagine what they are living through begins to point to the difficulties in processing additional bereavement and loss. It is challenging to write about as the layering of challenges, chaos and complexity that was faced by some participants does not make for linear or schematic presentation. However, it is of clear importance to discuss how central some of this personal moments of crisis were, as they were so intertwined with the narration and explanation of their caring role, and their bereavement.

While they were told by and experienced by individuals, we should heed the caution of Wright Mills (1959) that people "do not usually define the troubles they endure in terms of historical change and institutional contradiction" (p. 3). While unique to the individual, the troubles and life events described, were experienced by a particular range of participants within the sample. The biography which participants outline is often punctuated with traumatic events. There can be a cumulative effect due to the neighbourhood, health difficulties, limited employment, criminality, violence experienced, making it difficult to adjust to or successfully transition from the past.

As highlighted, there were notable absences. It is difficult to make the case for a silence, absence or lack of 'troubles'. It would be naïve to draw conclusions, based on less troublesome accounts, on the experience of those who were more affluent within this sample. Nevertheless, what it does

it highlight the compounding and clustering effect that others in the sample described at length and in detail. Their absence, and clustering, evidences that this is a public issue, or set of public issues, rather than coincidence.

These complicating issues for those living in the most disadvantaged circumstances were often part of the narrative of the participant, often without prompting from myself. The seeming ease with which these explanations were shared highlighted the fact that these life events were an essential part of their narrative and the story of their and their families, bereavement. Often in describing their grief, or situations/difficulties they faced before the death, it *had* to be couched in the other events going on at the same or similar time, or the preceding circumstances.

Overall, this chapter has evidenced how in describing their experiences of caring for someone at the end-of-life, and in their bereavement, other troubles and issues persistently had an impact and were interweaved with the very immediate and real pressures presented within their lives and families. The presence and relevance of these additional social issues, constraints, traumas, worries was unavoidable in their lives, and therefore they are presented here to give appropriate voice to ensure the findings of this research do not obscure these pertinent issues.

Chapter 5: Interactions with Healthcare Professionals and Organisations

5.1 Introduction

Throughout what might be described as their caring career, the participants interviewed experienced numerous interactions with professionals in many guises. This chapter will explore a major theme arising from the fieldwork interviews which was related to the manner in which participants frequently reflected on encounters with public, private and professional bodies. These interactions often reflected the different stages of illness or proximity to the end-of-life of the person they were caring for. In addition, other staff became involved when further support was required to provide adequate care, when bureaucratic assistance or clarifications was required, and finally when death and funeral services were needed. Trying to deal with multiple professionals with differing purpose and potential outcomes could be challenging as will be explored.

The interactions described by participants could be complex and where necessary will be described with as much context as is essential to convey the meaning of the story. In trying to understand the consequences of the differences in experience, the chapter will present a series of instances that highlight the intricate nature of these brushes with 'officialdom' and how these could continue to affect participants long after their loss.

A major and often defining feature of the narratives of their care role and loss, was the interactions with professional and other service staff which they experienced. This was a theme that emerged clearly and early from within the accounts. Due to the repeat interview method there was scope to further understand and explore how or why interactions were so significant, and for some participants it allowed them to reflect and raise or express additional considerations.

Firstly, healthcare professionals, the healthcare system, and what this meant for their role as a carer or how they felt it impacted on them and the person who they cared for, will be highlighted. This was a significant aspect of the accounts and as such will be explored in-depth. Following this, and

somewhat linked, interactions with police or coroners relating to the death will be briefly outlined. The experience participants and their families had with funeral directors will then be discussed. Finally, the focus will be to illustrate examples from accounts of participants and their experiences of the public sector and services, charities and others organisations relating to care, death and bereavement.

5.2 Doctors, Nurses and Healthcare Professionals

The wider academic literature on carers, illness and end-of-life highlights that interactions with healthcare professionals of all types, clearly determine the quality of experience of patients and their carers at end-of-life (Parsons, 1951; van Ryn and Burke, 2000; Pilnick and Dingwall, 2011). When carers and patients enter the healthcare setting they relinquish their control to the authority and expertise of the healthcare professionals, whom they trust will provide the care and treatment to improve or make stable the condition of their loved one, or make comfortable their end-of-life.

All participants were prompted to some degree on this theme and they discussed their interactions with healthcare professionals. For some, their experiences represented examples of good care that eased, to a degree, the crisis points of illness and subsequent death. There were also discrepancies in the manner in which communication aided or frustrated the support for some participants. Some of these stories that were shared told of perceived significant failings on the part of healthcare professionals as described through the retrospective memories of the participants. In certain circumstances this led to complaints, yet there were differences in who complained, when and how.

5.2.1 The Displays and Discourse of Knowledge

Participants shared accounts where either they had been hindered by feeling they did not have the education or language to communicate and achieve understanding with healthcare professionals, or felt they had to try to perform and display their knowledge. For some this was more difficult than for others, and this section will explore the different ways in which this was made manifest, as well as highlighting the similarities between accounts.

Pamela provided care for her mother, Betty, full time for several years. Betty had been paraplegic for over 20 years. There were occasions when Betty would be admitted to hospital due to other complicating co-morbidities arising from her paraplegia.

Pamela continued to provide care in the hospital setting, sometimes being there for 10-12 hours a day to wash, dress, feed and generally support her mother. Due to this she would have frequent interaction with ward nurses and also with the doctors and consultants responsible for treating her mother. Despite her prolonged presence in the hospital setting she often struggled to engage with doctors.

Pamela's lay and intuitive expertise of her mother's conditions and needs could have been informative and insightful when faced with nurses. She recounted an incident to me:

She couldn't move her legs – paraplegic, obviously – so you'd have to move her legs and they'd [nurses] say "Come on Betty, lift yer leg up", I said "She paraplegic, d'yer not read the notes?" (Pamela)

During interviews Pamela was similar to many participants in that she would refer to an over-stretched NHS. In her encounters with nurses she felt that there was often not the time available to enquire or understand, even less to build much rapport. This account was similar for many participants and often seen to be symptomatic of an under-funded NHS, rather than a complaint against the individual staff members themselves. Although unlikely to reframe this issue as a problem of productivity in line with neoliberal governance (Sturgeon, 2014), participants in this study clearly felt an under-resourced healthcare system was a barrier to accessing adequate medical attention.

If they explained to me more [...] Yea, the nurses they've got all this knowledge, I'm thick as pig shit, d'yer know what I mean? Explain to me and I know where I'm going, and then you see them flying around and yer think, I'll ask them then, "Just a minute, just a minute", n'yer think, "Well, I can't get a conversation cause they're busy" N'it does make you feel

awful, cause y'tired and y'worried, so it makes it ten times worse. (Pamela)

Pamela often blamed herself for these deficits in care, referring to herself as “stupid”; not having “the right words”; or not knowing the right questions to ask. This was exacerbated by doctors often not having the time to spend to talk to patients or carers.

The idea of needing to ask the *right* questions was striking. It was not only Pamela that described interactions in terms that resonated with this notion. Joy described asking for her daughter (a nurse herself) to attend consultations with her and her husband, Frank.

*I just wanted her there to, emm, give me her opinion. Did she think it was alright to go ahead with this operation on his legs [...] So that's why I wanted her there really, like a second opinion for me. And she did ask him questions that I wouldn't have thought to ask, but she did, y'know. Cause I think – I mean, I think I was – my mind was just on him, I didn't want him to go through a lot, if it wasn't gonna be a success. I'd have rather us just gone along. [...] And our Gloria said, “It's the best thing. Mother, just to leave it, and it'll be alright” y'know. And of course we just, err, went on.
(Joy)*

Joy had felt that she would be too emotionally invested with her husband to fully comprehend what was being described. This indicates an anticipation that there will be difficulties in achieving effective understanding. It required Joy to utilise the professional expertise that she was fortunate enough to have within her family to ensure that they were able to pose questions that might have otherwise gone unasked and unanswered.

Myself: D'yer think if Gloria hadn't have been there d'yer think it would've been different? D'yer think the specialist would have explained in as much detail?

Joy: No, I don't think he would, I think because she was there, n'of course she asked questions that I – well, I just wouldn't have thought of, n'that's, y'know, the benefit of having a daughter or a son with yer, because – when you get old, y'don't always remember what to ask, y'know, err, but our Gloria, I mean, it was good cause our Gloria did ask him an awful lot of questions [...] Without a doubt, n'I'm hopeless.

These interactions provide a discrete opportunity within which all understanding must be brokered. Yet these interactions are negotiated differently dependent on what the patient and/or carer are able to bring to the interaction with regards to their perceived level of capacity, education and willingness to engage.

This sets up a peculiarly problematic dynamic. Medical expertise is viewed as requiring the respect, deference and compliance of the patient (Lupton, 1997a), yet here it would appear that participants are highlighting that they felt there were further expectations of them to elicit the information the healthcare professional possessed. The participants had internalised an expectation that a particular level of education was required in order to facilitate medical consultations. This power imbalance of rights and responsibilities in medical encounters appears to remain problematic for some of those from working class backgrounds, as opposed to the more affluent members of the participants.

Pamela felt that her education (or perceived lack thereof) meant she did not have the ability to access the appropriate discourse that is associated with interactions with healthcare professionals. Yet she demonstrated that she had vast insight and lay experience of care. This represents different forms of knowledge and subjugated knowledge - the lay experience of care almost pitted against the professional expertise of the qualified healthcare professional. However, in such interactions the brokering of what is legitimate knowledge, as demonstrated by Pamela, can go on to affect the self-belief of the carer.

For Ian the notion that he lacked something, due to never having had formal education, was frustrating.

She said "What medical background do you have?" I said "None", she went "Oh right, it's just yer asking like pertinent questions" I went "Well, I've got a good vocabulary, does it mean I've got pieces of paper on the wall with my name after it? It doesn't" I said "I've got a brain". (Ian)

In his description of the exchange Ian got increasingly animated and annoyed as he described the interactions. Ian had spent time researching using the internet to seek to inform himself about some of the more intricate aspects of medicine. His knowledge of the health and medical issues particular to himself and his family was comprehensive, yet for it to have been such a surprise to the doctor was an affront to Ian and his perceived capacity to absorb and make sense of formal medical knowledge.

Formal training, education and qualifications are perceived to carry and accrue status upon the holder (Lupton, 2006). Yet not all participants had such qualified backgrounds. With some having no or little post-16 educational career this may have been judged to be in deficit. In these cases, it can appear to the carer that their knowledge of the person they care for is of lesser importance against the authorised expertise of the healthcare professional. Yet the narrative accounts highlighted here demonstrate the personal, intuitive experience required for caring and therefore a different type of practical expertise.

5.2.1.1 Reluctance at End of Life

Participants had a range of experiences in terms of how the person they cared for passed away. Yet a unifying theme for many appeared to be the reluctance of healthcare professionals to address end-of-life or palliative care. More than one participant found that healthcare professionals became less clear in their communication when it was obvious (not necessarily to the carer in the moment) that the patient was in the palliative care stage. Due to the retrospective accounts that the participants were giving they were able to reflect on the experience in its totality.

Debbie's mother had suffered for a number of years from COPD. She described how she had sought information and the outcomes of that.

I'd mentioned to them about palliative care, you know "When do you know when you're going to that stage?" and she said "Oh, don't worry about that, if it gets to that point the medical people will sit and talk with you", and nobody ever did.

(Debbie)

COPD is known to be difficult to manage and predict, a fact that Debbie was aware of. Yet the lack of open communication, regardless of the ability to give a prognosis, was a cause of disappointment and regret.

For Mary the end of her mother's life was traumatic, and whilst certain aspects of the care were laudable, the manner in which her final hours were treated was not ideal.

She was having like seizures every 10 minutes, erm, but she didn't know anything, but, err, so then the doctor came and I went out and spoke to him and he said "What do you want to do?" more or less, n'l said "I want her just to [pauses, cries] be peaceful". So they don't actually say to yer that they're gonna give anything to them, they don't say – he said "fine, as long as we know that's what the family wants, we'll put her on a drip". (Mary)

The language used was not clear and gave the family expectations that after her mother was "put on a drip" it would be peaceful and swift. Unfortunately it took nearly another 24 hours, with continual seizures before her mother died. The impact on the family was considerable and has led Mary to lie to her sibling to "protect" her from the true manner in which their mother died.

Natalie's experience highlighted the way in which information might be intentionally withheld. She described the moment she found out her mother was at the end-of-life stage from the oncologist who had treated her mother for nearly a decade.

Natalie: *She said “Um, the chemo hasn’t been working”, I said “Why didn’t you tell me?” she said “Cause you couldn’t have handled it”, she said “And if” – Dr S felt if she’d have told me that this is it really, then I’d have lost my spark and Mum would’ve lost hers, she said “So it’s been best to keep you in the dark”, she said – she did admit, she said “Maybe I should’ve told yer”.*

Myself: *How did you feel about that?*

Natalie: *I was furious at first, I was livid, and I thought she had no right, I should have been told everything because – I don’t know if we’d have stopped treatment to be honest, if we’d have known sooner.*

At the time Natalie had little time to process the information and it took her some time into her bereavement to come to terms with the rapid decline and death of her mother. Even two years after the loss she struggled to settle on whether this course of action was for the best. The lack of information allowed her to spend time with her mother, however she was left in her bereavement with the reflections of what might have happened or how it could have been dealt with differently.

These accounts from participants indicate a clear deviation from the Gold Standards Framework (GSF) that is in place in the UK to provide a framework of practice to healthcare professionals dealing with patients and their carers/families at end-of-life. From the point of view of the patient and carers the GSF should enable “all frontline care providers in any setting to give care that is proactive, personalised and well-coordinated” (National Gold Standards Framework Centre, 2015b). None of the participants referenced the GSF and this may indicate that there was a lack of clear, or indeed, any communication regarding the end-of-life and what that would constitute in terms of symptom management, involvement of other services or professionals, or what they should expect.

For those that did have clear communications from healthcare professionals at end of life it signalled certainty and that - whilst upsetting - allowed for an emotional preparation.

I think that's the hardest thing I've ever done in me life, when he was lying and he said "I've had enough", n'I had to walk out to the doctors' station n'tell them, and it was like the long – it was like walking the green mile [...] But after that the practicalities of the, errm, end-of-life care were fine, n'I said goodnight – we said goodbye that night before the drugs really kicked in, n'he died the next day. (Linda)

Linda's husband Eric suffered with lung cancer and she noted her positive experience of the palliative care he received. He died in hospital and she found the communication between the healthcare professionals and herself and family to be extremely clear and compassionate. Whilst the loss of her husband caused a great deal of loss and grief, she was able to take solace that his death was as comfortable as it could have been. It was what could be considered a 'good death' (McNamara, 2001; Howarth, 2007a).

Ken similarly noted that the clarity of communication between his family and his wife, Ruth, aided her palliative care. After being diagnosed with a brain tumour and given a prognosis of three months the care and communication was very clear and swift. Ken stated "It was a good end really". Ken, Linda and Tom all recounted good communication, some level of control and good pain management that allowed a peaceful end and death for the person they cared for.

5.2.1.2 Who Is Worthy

Sheila lives in an area of Stockton-on-Tees that has been characterised by long term deprivation. Her son, Carl who was 38 years-old at the time of his death, had been released from prison months before he died from pancreatic cancer. For many years he had struggled with drug and/or drink problems. Yet during his time in prison and upon his release he was following a methadone programme with the aim to be drug free.

Carl had presented repeatedly with painful symptoms to doctors whilst in prison, and subsequently on his release. Showing symptoms of dramatic weight loss and extreme back pain, he hadn't been able to lie flat on his back to rest or even sleep for several months.

Myself: D'yer think they just didn't tek him seri –

Sheila: Serious? Nor, because of his drugs.

Sheila knew something was wrong and rang local private and NHS hospitals; "You can pass me from pillar to post, but am not getting off this phone", in order for someone to scan Carl to investigate further. On the phone to the third hospital she rang she told me how she broke down whilst speaking to a nurse:

I said "My son is dying in front of me and nobody's taking any notice cause he's on methadone, they're treating him for constipation, they're giving him movicol, movicol, he was in the hospital last night, they haven't done nothing for him, they haven't even give him any painkillers". (Sheila)

Due to her intervention he received a scan and was given a diagnosis of pancreatic cancer. He was already in the terminal stages. The family went home. Upon seeking support and a programme of pain management, a local GP came to give a home visit for Sheila's son.

When he was diagnosed on the Friday, we got the doctor out. When we come home, we got the doctor out and I said to the doctor "Right, he's got pancreatic cancer, it's nothing to do with constipation, he doesn't want no more movicol" I said "He needs pain relief, he needs something for his pain". Do you know what he said to me? Dr P from down there, "I'll put his methadone up 5 ml – I'll put his methadone up from 15ml to 25 ml" I went to him [Starts to shout] "You're having a fucking laugh, aren't yer?" and he looked at him, n'I said "Who are y – methadone? What's that gonna do? He's got

cancer”, “Well, there’s nothing I” – honest, I could’ve shook him. (Sheila)

Sheila clearly felt her son was treated differently because he was on a methadone programme. This was stated on several occasions throughout the interviews. It was clear that there was stigma attached to Carl and his treatment. It was something the family had come to anticipate and try to mitigate. Sheila described a conversation upon admission to hospital:

I said “So can you give him something for his pain?” cause he was in agony, “Yes, we’ll sort him”, I said “You’re not just gonna look at him and think ‘Drug user?’” (Sheila)

An antidote to the stigma surrounding drug addiction, suggested Sheila, was better education. Having previously had particular view about substance misuse, she had based her reactions and opinions on drug users on pervading societal rhetoric which demonises the individuals. These preconceptions were challenged when she began attending a charity to support substance misusers and their families. Sheila felt she observed stigma clouding the will of the healthcare professionals to properly treat and support her son. Carl’s life appeared to be deemed to lack sufficient worth.

The feeling that the worth of their loved one was devalued was also evoked by Ian in his account of the interactions with a GP. After his uncle Nigel had surgery on his stomach he was prescribed liquid food supplements, which he needed for a period of time when his stomach was too tender to receive solid food. The GP had visited and Ian described the experience and the doctor’s reaction:

“Aw, I think you’ve had enough of them, they’re quite expensive”. Literally, that’s a direct quote. So we call her Dr Death. (Ian)

He described the GP’s treatment as “a joke” and the more interaction with doctors Ian and Nigel had the more it made them “feel powerless”. Ian was critical and offered suggestions of why Nigel had received such poor treatment in the run up to his death:

It's about life and care, but it's - I'm telling ya, it's all coming down to money, and whose liable for it, whose gonna get it in the neck. (Ian)

Debates about the cost of healthcare and support for the smooth running of the NHS are much publicised. Many participants spoke of this. Ken, a retired draughtsman living in a relatively affluent area of Middlesbrough, had a more positive experience of interaction with the medical system than those described previously, stating:

By and large I would say the care and help and assistance we got was excellent, apart from the management and the people on the end of telephones. (Ken)

Ken's wife, Ruth had been diagnosed with a brain tumour and, after taking the decision not to have surgery, she was given a prognosis of three months to live. Her remaining time was made as comfortable as possible and Ken spoke highly of the support they received in terms of GP visits, district nurses and equipment for the home. Of all of the participants Ken was in the minority in that Ruth died at home.

Where Ken did have difficulties, with regards to calling the NHS support phone lines, he felt that the problem lay elsewhere. He cited issues with computer systems failing to log calls or adherence to scripted guidelines on calls that slowed down access to care. His interactions with healthcare professionals were very different to the experience of Ian, Sheila and others:

Our Doctor was very, very good, he sat down with her on two or three occasions and talked through with her it all, he was excellent in the way he co-ordinated things. (Ken)

Where other participants had suggested that they had not felt worthy of the support and care they anticipated for their loved ones, others felt that at the time and attention they had received a good standard of care. It appeared in their accounts that whilst referenced as being good it seemed not particularly noteworthy of elaboration. It may have been that good care was an anticipated and expected standard of care, therefore appeared to be difficult

to describe in further detail. The positive ways in which this was conveyed was an interesting discrepancy.

For Ken there was never any sense that there was a disconnect between himself and the healthcare professionals with whom he interacted. The care he described, and the manner in which he described it, was very complimentary. There was no sense that himself, Ruth or his family were judged to be any different, or less deserving of the high standard of care and treatment they received.

This was not limited to Ken however. Linda, Tom and George also described their experiences of healthcare professionals and their interactions in very positive terms. Their positive experiences meant that it was sometimes difficult to elicit rich accounts, such as those painful recollections from people who had suffered failures of care, as the standard of care was satisfactory. Those who had experienced good standards of care did not extol it as such, or with as much detail and depth. These participants all tended to represent those who were more affluent within the sample. Their interactions may have been more smooth and positive in part due to this.

5.2.1.3 Cancer, Hospices and Macmillan

The difference in experience cannot be explained in terms of type of disease. Whilst Ken and Linda both cared for someone who suffered from illnesses with fairly predictable trajectories, and thus with clear end-of-life pathways, so too did Sheila's son, Carl. Yet the experience of formal palliative care by Carl and his carer differed significantly from that of Ken, Linda and also of Tom.

Hospices have traditionally been thought of as the preserve of the middle class, and historically accused of being run for and by a particular demographic (Lawton, 2000; Allen, 2007). When Sheila's son, Carl was dying of pancreatic cancer the family felt the only option they had was to admit him to a hospice to try and manage the pain he was in. Initially he had resisted going, but the family discussed it with him and they all agreed it would be for the best. However, the care received led to a dispute and an abrupt return home.

Got him into the hospice, she [palliative care nurse] said "Why's he sat up like this?" I said "He's never laid down since August", "Well that's no good, he's so uncomfot" – I said "He's not uncomfotable, he's comfotable sat on the bed like this" and that's how he was. So this nurse, whoever she was, errm, "Oh we'll have to get that sorted" I said "You won't have to get that sorted" I said "You won't have to get nothing sorted, that's how he is" I said "Until yer try'n control the pain n'what'have'yer". [...] I went for 11 [o'clock] and there was a couple of his mates there and they had a screen round his room, so the nurse – I said "What's this screen round his room for? Why can't we go in?", she said "Oh well, we're trying to get him settled n'everything", I said "Oh fine", so made a cup of tea and had a laugh between ourselves as you do. Anyway, I said to her "Ee, I've been here an hour" I said "What about that screen? Why isn't it down?" she said "Oh, we're just sorting him, it's gonna tek a while n'tha" I said "Oh fair enough", cause they know best, they know what they're doing, d'yer know what a mean. So fair enough, anyway, I don't know whether it was about 1 or half 1. I said – she passed again, I said "When am I gonna get in to see me son?" she said "Oh, just a couple of minutes", I said "Again a couple of minutes?" I said "You've been saying that since half past 11". But then you realise it's the [hospice], people are dying, pull back, so shut up. So anyway, we pulled back, anyway, I just seen doing that with the screen, so I said right, so I was off straight away, so I walked in, n – I – the woman – I could've slapped her, I could've slapped her, she said "There you are, all nice and comfotable" and he was laid, not flat, but sort of laid like this, and he's laid, and it was a relief actually to see him, I thought "Well he is comfotable, he's come in here, he's resting, it's peaceful, it's" – yer know what a mean. Walked over to him and he was like – didn't know what was going on, so I got his hand

and I rubbed his arm [rubs her own arm], "Are yer orite [alright] son? It's Mam. Carl? Are yer orite son?" he just scream – not screamed, but grunted [Makes prolonged, pained groan] I said [Slams her hand down and raises her voice] "Get this bed up now", cause I was fuming, gets the bed now "Well, well, just but"- I said "It's up. There, son" I said "Is that better?" [Slams hand down again] Then he grabbed me hand, I said "There are yer orite?", but it made me feel that they were like say – "You will lay down" like a kid "You will lay down, you will lay" – n'this is how I felt they'd gone on with him, so in the finish he's laid down just to shut him up. He was in agony. So anyway, she flew out, I said "Right, he's going home" she said "Yer can't" – I said "He's going home".

This passage has been included to highlight the struggles with which Sheila had describing this experience. She was highly emotionally charged and even when the events had happened several years before, this incident contributed significantly to the manner in which she viewed hospice care as being something which she and her family did not conform with.

Sheila deferred to their superior knowledge and admitted at the time she felt that "they know best". Upon her realising her son was in tremendous discomfort, Sheila could no longer carry on the pretence of adhering to the tacit code of conduct within the hospice. Part of this code of conduct was to remain calm and peaceable: "pull back, shut up", and to adhere to the recommendations and actions of the palliative care staff: "they know best, they know what they're doing".

She went on to describe how she had a confrontation with the palliative care nurses and managers of the hospice. After her continued protestation her son was discharged back into the community and was able to die at home.

This incident has forever tainted Sheila's views of hospice care. Having glimpsed first-hand the treatment provided she accepted they did provide care and make comfortable some; "that's fine for them that can do it". Thus,

suggesting that not all can conform to the expectations and regime of the hospice.

Sheila's account contrasts significantly with the experiences of Ken, Tom, and Linda, who were all able to access support in a manner that suited their needs and allowed them to give their family member a 'good death'. Their accounts highlight the relative ease with which they could relate to healthcare professionals and communicate their wishes and needs. However, for Sheila, whose whole experience up to and including Carl's admission to the hospice, appeared to convey distance and judgement between herself, Carl, and her family, due to his substance misuse, and their differing expectations of care.

5.2.1.4 Nature of Death

The place of death varied throughout the sample. The majority of cases in the sample had relatives who died in hospital, however this was not through choice. Evidence suggests that an 'at home death' in the UK is the ideal for 67% of the population (Shucksmith, Carlebach and Whittaker, 2013). Mary, Linda, George and Debbie all suggested that they had requested or made attempts to arrange their loved one being at home unsuccessfully. Largely this was due to factors outside of their control, such as lack of appropriate transportation, pain management not available at home, or that the person was too close to death. Despite these factors being outside of the carers control it could lead to feelings of guilt in their bereavement.

Ken, Tom and Helen were able to facilitate their loved one's death within the home. It was described in positive terms and they manner in which they were supported to have the death at home allowed for more normality, however brief.

He got his spirit got right up, he was watching his Sky telly, he could see his garden in the sunshine, every single thing – he had a Chinese from his favourite Chinese takeaway, all the things of normality, he was shouting us up on a normal to tell our Mam to get up to go to the centre which he used to do before, n'it was like unreal having him back. (Helen)

The value of having their loved one home when they may have previously been in a hospital or care home setting was clear. Participants felt this was the ideal, despite the difficulties that came with it regarding the practicalities of healthcare professionals having to visit in the home setting.

As described in the last section the manner in which Carl finally achieved a death within the home was stressful and in opposition to the wishes of the hospice staff who did not want to see him discharged. Similarly Ian's uncle died at home, in no small part, due to Nigel's refusal to allow or engage with any further medical intervention.

5.2.1.5 Complaints

Across several accounts participants described how the care which their loved one received fell short of their expectations. In some instances this led to an informal or formal complaint being made with the ward or organisation responsible. Yet there was a range of understanding amongst participants as to how to make a formal complaint, and different feelings about being personally empowered to do so or confident that there would be a worthwhile outcome.

Natalie had provided care to her mother for a decade, and this changed the way in which she approached situations regarding the treatment of her mother.

I lost my temper with the sister that night, because she was getting annoyed with me because they were busy talking and I kept interrupting. I said "Well, let me get my Mum settled and know that she's safe and you can get back to your gossiping", and err – oh, I did put a complaint in about that.
(Natalie)

This type of confrontation and forthright willingness to make a complaint was not in the usual character of Natalie, she noted:

It changed me as a person, because I was a shy little mouse. I wouldn't've said boo to a goose at one time.
(Natalie)

Whilst this change in character was perceptible to herself and those around her, it was born of an awareness that the treatment received was poor in many respects and that there were ways in which it could be addressed formally.

Debbie had a breakdown in communication (as noted previously in this chapter) when her mother, Eleanor, was in the late stages of terminal COPD. She had contacted a patient liaison service to request further details after her mother's death.

Myself: How did you know to go to the, was it patient liaison did you say? Cause I've never really heard of that?

Debbie: I think they call it patient liaison, well I did – I was a hospital secre – I was a secretary for a hospital, an administrator, my first job, but that was a long, long time ago.

Without this prior knowledge Debbie might not have sought out the medical records which she obtained in order that she might draft a letter to the hospital regarding the failures surrounding the care of her mother.

But you know they won't do anything, y'know? And the fact that they were saying – just the – I suppose to them it's – it's very personal to you, so you remember everything, I suppose they don't. (Debbie)

Whilst caring for her husband, and then also her mother, Linda had referred to feedbacking complaints or raising issues both formally and informally with those treating or caring for her loved ones. Yet even she at some points struggled, and after she had described an incident with her Mum, I asked:

Myself: Did you raise that with them?

Linda: What's the point when me Mam's gone?

It is notable that Pamela, Sheila, Ian, Mary, Helen and Joy all had significant elements in their accounts which described failure of care or considerable lack of support. However, none of these participants made a complaint. These participants were often those from the most disadvantaged

backgrounds. Even where their accounts led them to anger, upset and distress, there was never any discussion of potential recompense or justice. This may have been down to several factors such as; lack of awareness, limited time or ability to do so, or a feeling of apathy that their complaint would not have been acted upon. Overall, it would appear that some people are not having their concerns of failings heard.

5.3 Police and Coroners

In the event of a death which is sudden, or unexpected to healthcare professionals, there may be the need for the police to be involved to question the person with whom the deceased had contact with. For Ian, Joy and Angela to some degree their experience of death triggered bureaucratic procedures. In all cases the deceased had been ill, and known to be ill, for a significant amount of time prior to the death. However, as the death was sudden and not preceded by rapid deterioration or end-of-life signs, it was treated as something which had to be investigated (Gov.uk, 2019).

Joy's husband had been diagnosed as having an aneurism which, if treated, would involve risky surgery; they were advised that if left he could expect to live approximately another 5 years. However, he became ill very suddenly and died within hours. After being escorted from the room Joy was approached by a police officer who stated that she must answer some questions, "then you can get the death certificate". After some initial frostiness due to grief and surprise at the police presence, Joy co-operated.

Joy: The copper knew we were upset like. Anyway, he asked me his [husband's] age and his name and really nothing, or just "When did this happen?", I said "This morning" I said "About 4 hours ago" y'know, n'err, anyway he went.

Myself: So was that quite upsettin'?

Joy: Yes, it wor.

Myself: Did that make yer quite angry?

Joy: *Yes, it did, because I didn't see the point in him coming and asking, if he hadn't had this aneurism, err, then and he'd had died – just gone, I could understand it, that maybe they would think somebody had done something or owt like that. But when somebody dies of something that doctor can say –*

Myself: *That they know about?*

Joy: *Yea, what's the point? There were no point to it, d'yer know what I mean? And it upset me, it made me feel really angry to be honest.*

This incident was moments after Joy had been led out of the room where her husband had died. There had been no warning from any healthcare professionals that this might happen. Her anger and distress - despite being evident - was not adequately catered for. Prior warning would have allowed Joy the opportunity to prepare and would have lessened the shock.

When Ian's uncle Nigel died at home he had to call for an ambulance and the paramedics had to request that the GP attend. Ian refused the GP attendance and as such the GP requested that the police attend and then ordered an autopsy.

Me: *How did that make you feel though?*

Ian: *I wasn't bothered because I know how things work like that, so I knew I had nothing to hide. It didn't bother me until afterwards, I thought "That stupid doctor", der yer know what ah mean, "She wasn't satisfied, so what, she gets to say all this? Gets him cut open, n'get all his organs n'shit out".*

The nature in which sudden deaths are dealt with is highly regulated and bureaucratic. The assumption would be that there would be standard procedures applied to all. Yet the lack of communication, or, in the case of Ian the history of previous failures of communication with the GP, led to these being particularly bothersome and unsettling encounters and outcomes.

5.4 Funeral Directors

Several participants noted – as a contrast to the sometimes troubled relations with health professionals – their positive experience with funeral directors. The impact of this could be felt in small yet meaningful ways. Memories were shared by participants that highlighted how important it was that they and their families were treated with sensitivity and tact. Despite the funeral industry now being a mass customer service driven sector, it appeared that those interviewed received individual and sensitive treatment.

The seemingly personalised and attentive care which participants referred to was often apparent in very small acts of sensitivity or subtlety. Helen spoke of how, in describing her deceased fathers' love of the local football club, Middlesbrough (commonly referred to as Boro), the funeral directors arranged for the funeral cortege to be driven into the grounds of the stadium. She had not requested, or even thought such a thing possible. Yet it meant a great deal to her family to be able to pay tribute to in this way.

Successfully organising a funeral was not the only thing for which funeral directors were praised. The death of Pamela's son, Luke, was due to suicide, which she was felt was linked to his drug use. The funeral director dealt with their loss very sensitively by accommodating the family's individual responses to the traumatic and sudden death. Both Pamela and her husband attended the funeral directors every day to visit Luke's body in the chapel of rest. They had dressed him in his favourite piece of clothing, his hoody. Pamela was concerned about changes to his deceased body. The funeral director was perceptive of this and informed her that he had arranged the hoody in such a way that she would not be able to see the marks on his neck from the ligature with which he had hung himself. This delicate and sensitive gesture was much cherished by Pamela, in that she felt she had been given an additional opportunity to be with her son, before his cremation, that she would not have otherwise had without that small action.

Arguably it is the role of funeral directors to demonstrate and facilitate these mourning rituals, practices and opportunities, and therefore these actions should not be given too much emphasis. Yet for the participants they were

rare fragments of positivity in an otherwise painful and sad narrative of death and loss.

The cost of a basic funeral has increased between from 2004 and 2015 by 92.3%, with the average cost in the UK of the most basic funeral being £3693 (Sun Life, 2015). This highlights the increasing financial cost of this end-of-life necessity. The cost of funerals was referred to by some participants.

Why are funerals so expensive? Yer flarin' [cremating] the person up – sorry, the remains. It's like – how many people der you know, my uncle was one of them, me Mam, me Dad all me brothers and sisters, I'm one of them; "When I'm dead I'm not bothered, just whatever, get rid of me, bumph, don't worry about all this horsedrawn cart, n'this thing. N'they all say it, and it's like when it comes to it, you have to pay this, n'you have to pay that. It's like "What yer doin' to it like?", n'the cheapest coffin's like £275, right, and it looks alright, it looks pretty decent, n'that's the basic one, n'it's like [starts to laugh] yer just flarin' him up. (Ian)

Due to the manner in which most participants cared for their loved one, many had arranged and anticipated how the cost of the funeral would be covered. Yet even where this was done it was notable that the cost was still referred to as significant to the participant.

You didn't get much change out of five thousand. You want to give 'em a good send off, don't you? (George)

Meeting the cost of paying for a funeral was not explicitly asked in interviews and for those from the most affluent backgrounds the money or cost was never raised. The focus of the narrative was more often concerned with the ritual, tradition or practicalities of the day. The absence of a description or concern with cost may reflect that due to their relatively comfortable financial position, meeting the cost was not noteworthy, or had been previously accounted for.

Those from more deprived backgrounds in the sample were also those who lost loved ones who were comparatively young. Ian lost his uncle who was 63, Sheila lost her son who was 38, and Pamela lost her son who was 23. The relatively young age, and the lack of financial resource within these families meant that the funerals either came as a surprise or that there was restricted money to pay for a funeral.

Ye'don't say to yer kids "Do you wanna be buried? Do you wanna be thingwied?" My Mam – I don't wanna be – me Mam and me Dad tell me, you know, what songs yer Mam likes, yer know what yer Dad like. But how do you go and ask a 23 year-old son? You think he's gonna bury you. I tell him what I want. I didn't have a clue what he wanted.

(Pamela)

Due to the nature of recruitment and how the research was framed all participants had anticipated the loss of the person whom they cared for. In fact, Pamela got involved in the research due to the loss of her mother and father, yet the inter-connected and multiple close bereavements meant she would also refer to the loss of her son. In the quote above she gives an insight into how sudden or unexpected deaths can have an impact. Whilst they were able to cover the cost eventually, it was unanticipated in ways that continued to stay in Pamela's mind some time after the death.

Deaths within families can represent a significant financial and emotional cost. When Sheila lost her son, Carl, she noted that "the lads" (Carl's friends) took care of the cost. The implication was that she might have struggled herself and also that due to his close, and at times criminal, past with these men, they felt a sense of duty and a desire to ensure their friend had a "good" funeral.

He said to me "Mam, the lads'll sort it, don't you worry about a thing". (Sheila)

For Ian, the lack of money to finance a funeral (as described above) necessitated his having to access the social fund funeral payment (SFFP) to subsidise the cost of the funeral for his uncle Nigel.

Upon interviewing Ian he was having ongoing difficulties with regards to the release of the money. Having followed all the instructions set he found himself having to arbitrate the situation as the funeral directors had asked for payment and had not heard from the SFFP, yet they had undertaken another SFFP funeral around the same time and they had received payment for that one. Ian contacted them to find out where the situation stood.

So I rang the DWP up and this woman said “We can’t do it for 21 days, blah blah blah”. I told ‘em what the funeral service said, “Well there’s a case there that they’ve dealt with in a few days”, and she said “Oh, have yer posted” – “Yea, and I’ve sent it recorded delivery, d’yer want the, err, details of the receipt that I’ve got in my hand”, “Oh no, I’ll just go through it” and that got her back up then and I thought “Yea, see get some attention off yer” and then she said “You’ll have to wait til the 17th before they’ve made a decision. [...] And I don’t wanna ring the funeral director and start giving them excuses, cause it might come across as if I am giving them excuses and I’m not. (Ian)

This left Ian trying to decide how best to deal with the situation, as he did not want to be viewed as deviant or evading payment. These concerns meant that at a time of attempting to adjust to the loss of his uncle, who he cared for and lived with, he was concerned with the financial ramifications of if, or how much, the SFFP would contribute to the cost of the funeral, and if it would be best to make a payment to the funeral directors as a gesture of intention and assurance that the funeral would be paid for.

The SFFP has come under criticism for being outdated and frustrating (Cullen and Pearlman, 2012; Foster and Woodthorpe, 2013). The eligibility criteria are unclear and communication can be difficult. Applicants could often wait a long time to receive a decision on their award. The amount awarded is often far less than the actual cost of a funeral currently in the UK. At the time of interview Ian had not been told if he would be eligible, or how much he

would be eligible for. This prolonged the unease with regards to closing the outstanding balance of the funeral.

Poverty, restricted finances and uncertainty can impact significantly on the bereaved when attempting to arrange or pay for a funeral. Where possible participants drew on the support of friends and family, but in the case of Ian this was not enough and he required state support. As previously indicated, those from affluent backgrounds rarely commented on meeting the cost of a funeral, or it being unexpected. This could reflect a reservation with regards to discussing money. Yet, given the evidence, it is more likely that they found themselves in positions where it was not a noteworthy aspect of their experience.

5.5 Agencies of the State, Charities and other Organisations

Throughout the life course the changeable nature of living and familial circumstances can alter the level of need participants could find themselves in. This can be a change in financial circumstances due to moving from employment to unpaid care, changes to rental situations due to a death, or change in the level of additional support required when providing care for someone with deteriorating health. All of these examples can necessitate interaction and brokering with housing or support organisations and services, and this can lead to confusing, distressing or frustration situations to arise.

Where the state and in particular local authorities are involved there can be a great deal of bureaucracy that is pertinent to the situation in which the family may find themselves. However the knowledge required to navigate bureaucratic systems is esoteric, niche and often time-limited due to the changeable nature of social policy. Attempts to understand, navigate and sometimes advocate the lines of these policies was an additional way in which carers would assume responsibility. It required what could be a demanding amount of knowledge, skill and negotiation skills, and these were not possessed by all.

George was caring for his wife Judith who had been diagnosed with early onset dementia in her fifties. Her condition deteriorated over several years and her mobility was becoming increasingly difficult. After an assessment by

occupational health services George was told that it would be advisable for a stair-lift to be fitted.

Myself: And did they send out anyone to come and assess your situation?

George: Yea, I think they did, as I say it wasn't the people that came to visit us that was the problem, it was higher up. We asked them to come and see for themselves, but they wouldn't – just sat behind their desk and all the rules.

Myself: I guess it's much easier to say no if you don't have to face the people you're saying no to.

George: That's right. So, I think in the end the social worker said "If you're going to say no to a stair-lift, you can't just leave 'em", so they knuckled under and we got a stair-lift.

There was resistance from the local authority due to the cost of such an adaptation being fitted. The social workers helped to advocate and put pressure on those higher in the local authority. After nearly a year they received a stair-lift. In the meantime the family had to struggle to provide the care that Judith required and this caused great distress.

5.5.1 Sanctions and Bereavement

Pamela had (and still had upon the final interview) many care roles, and, in addition to caring for her mother, also provided care to her father. He had to have surgery after which he became ill very suddenly. The anaesthetic had triggered a condition similar to dementia. He deteriorated rapidly and after attempting to support him herself, Pamela admitted she could not cope and he entered a care home.

During his time in the care home his stay and care was paid conditionally by the local authority. Her father's condition was reviewed on a 6 monthly basis. Pamela described this as, when he was deteriorating the local authority paid, when he was deemed to be improving the family received the bill for the care.

Subsequently he passed away in the care home. Five years after his death (in which time her mother and son had also died) a historic debt was raised by the local authority. This came as a surprise to Pamela who found herself liable to pay the £3000 debt.

Upon seeking clarification, Pamela was told that, due to an administrative error, the debt had previously fallen through the net. Yet they insisted it had to be paid, and she was liable for it. However, the family was not happy. On her behalf her sister attempted to challenge it. Both attended the local council to discuss it. Pamela stated that her sister was better educated, and able to access and reflect the discourse expected, than herself and more willing to dispute the debt. However, when the conversation became heated Pamela explained to me she intervened:

“Just forget it, and I’ll just pay it, it doesn’t matter”, but that’s – I said “It doesn’t matter”, y’know I just don’t want Mam and Dad’s name blackened ‘em, and that’s the end of the day, isn’t it? So, I’ll pay it, it keeps the peace.

Pamela was on Job Seekers Allowance (JSA) after being deemed fit to work despite having arthritis. The debt was £3000, not an insignificant amount. She did not have the means to repay this and a payment scheme was agreed upon. The debt was to be taken from her JSA of £144.80 (as of 2014/15), at a rate of £10 per fortnight. It will take her 11 years and 7 months to clear the debt.

From discussion there were possibly grounds for this to be contested. In asking her throughout the time we spent together in these interviews, if she would consider appealing the decision, she felt very much that there would be no point. Pamela appeared to have accepted that contesting the debt wouldn’t necessarily give her the desired outcome, and would in fact, in the short term cause more frustration and upset. It was easier to accept, begin the repayments and adjust to the loss of income of 7% for a significant time to come.

Pamela faced a bureaucratic system that, due to an error, deemed her a debtor years after the event and the loss of her father. This debt had to be

repaid. However, for Pamela it infuses the existing loss and bereavement with further emotion and grief. I would appear, she repays it due to feeling that she cannot leave a legacy of debt against her parents' name.

I mean, I just – it has to be paid, it has to be paid, y'know, I don't want my Mam and Dad's name going down. (Pamela)

Pamela is honouring a debt that they cannot repay. This may be so that they are remembered as trustworthy individuals who were not a credit risk. In doing so, it will act as a continuing and periodic reminder of the ill-health of her parents and their consequent deaths. Without negotiation or compromise Pamela was subject to rules and sanctions that had to be adhered to.

Sheila, her son and her family had to make changes to their lives in order that they could avoid his daughter, Paige, being taken into care by social services. Sheila stated in part of her description of her son's drug addiction that he hadn't wanted to go on a methadone programme, and rather completely abstain from heroin, "but he had to on account of Paige", (his daughter). Due to the drug addictions of her son and his partner, Sheila had temporarily taken kinship custody of her granddaughter, Paige, and Carl and his partner. Sheila described an interaction between her husband and the social worker upon hearing that social services were potentially going to take their granddaughter into social care:

"Yea, we're gonna take responsibility, we will [...] supervise them" he said "They're coming home", "Are you tekking the 3 of them?" he said "Yes, we are, we're tekking the 3 of them, they're coming home". So we had 'em home here for 3 month. Anyway, she went back with the bairn and Philip – she used to come like here, but he couldn't – he wasn't allowed to go there because she was on a methadone programme and she was doing fine, but Philip was still having these relapses. So, we accepted this, anyway, he managed to do it, so within 3 month they were all back together, which was marvellous. They were doing so well, cause he was on a methadone, she was on her methadone,

I mean, I don't like methadone, but it does get 'em on the – it does give 'em a bitta life back, if you know whata mean?

(Sheila)

As part of the agreement with social services to have care again of Paige both parents had to adhere to a methadone programme. Being open with, accepting the conditions and meeting the requirements of an arm of the state was normalised for Sheila's family and her son. In order to avoid further prison sentences or to be deemed a good parent Carl could not resist the terms which were imposed. Living within these circumstances and, as these examples suggest, constraints became habituated and therefore illustrated a different set of experiences from other participants.

Sheila, Pamela, Ian and Helen lived in areas with low levels of income, and high levels of crime. It was not uncommon for their family or their wider networks to be involved with crime and/or substance misuse. Poverty is often linked to debt and unemployment, and additionally poor health, criminality, drug or substance abuse. Those encountering these issues are likely to require support from services, or have constraints or targets attached to behaviour to demonstrate willingness to conform to what is valued and play the role of the good citizen.

Similar social issues that conferred particular expectations or sanctions from outside authorities were entirely absent from the accounts of the more affluent or middle class counterparts of this research. Whether this is due to either their reluctance to share this type of information, or simply that they had not experienced these sorts of issues could be questioned.

5.5.2 Charities and Available Support

While the National Health Service (NHS) is the primary provider of healthcare for the majority of the population of the UK, and will diagnose and treat the vast number of illness and diseases, it is not the only service to provide palliative care. Hospices tend to be viewed as the specialist sites of providing palliative care at the end-of-life. The first hospice, as is thought of today, was the St Christopher's Hospice opened in London by Cicely Saunders in 1967, and since has proliferated into a network of palliative care support much

beyond the UK (Oliviere, Monroe and Payne, 2011). There are two main hospices in the Teesside area and service the population.

In the UK it is notable that health related charities dominate the charitable sector and receive the biggest amount of charitable donations (Birkwood, 2016). Their importance and prevalence is significant in terms of funding research, providing information and advice, even delivering direct treatment for patients and support for carers and families. Carers may have access to carers' support agencies and charities. Each local authority commissions services and support to be provided to those in the community who are carers. Uptake is not known, due to the difficulties in identifying carers, or carers identifying themselves as undertaking care work.

Bereavement and grief can bring a range of challenging emotional and physical responses. There are a number of specialist bereavement charities and counselling services, Those who are suffering the grief of losing a loved one may have access to bereavement support if they are made aware. The NHS may signpost to these support organisations. However, it would appear that there is little to no targeted support of the population of bereaved carers.

Whilst some participants were recruited through charities and not-for-profit organisations most of those interviewed had limited contact with these. The contact, support and help they did receive was sometimes piecemeal, usually relating to one very small specific concern (e.g. mobility aids, benefit entitlement, etc). Yet, for some, such help was more sustained. After the death of her husband Joy found that the changes to her pension, rent and council tax were very confusing.

Anything you want at the council you seem to be waiting weeks. And yer go and yer ask for different people – and the other thing is [...] it seems ridiculous the way they put it on the paper, y'know. "Your rent now is so-and-so, and so-and-so", and they're telling yer how much the rent is on the place [...] But then it said "Yer – but yer allowed so-and-so, so therefore y'pay so-and-so" And then it goes onto sommat else. Instead of just putting down your rent from now on is

going to be X amount of pounds – nothing as simple as that, just pages of all sorts of stuff that neither makes sense or anything else. (Joy)

Both of her daughters tried to help where possible, but as they lived in West Yorkshire this could be challenging. Joy was supported by the local carers' organisation when she cared for her husband. As Joy and her husband had regularly attended support groups, the carers' organisation went beyond their usual remit and offered to support her as a bereaved carer. This allowed someone to come out and talk face-to-face with Joy and call the requisite agencies on her behalf.

Linda also reported receiving excellent support from a charity. When her husband was terminally ill he had a dedicated Macmillan nurse, "who was absolutely fantastic".

I was in constant touch with the Mac nurse, erm, I knew things weren't right, so the palliative doctor came out with the Mac nurse, arranged a blood transfusion, things improved a bit. (Linda)

The additional support from the Macmillan nurse helped to broker access and advocate for further treatment on behalf of the patient and carer, when it was deemed necessary. Linda felt comfortable in contacting and seeking additional support. There were clear benefits for those that felt able and aided to navigate the system and seek support. This was not the case for all participants.

Several participants that it might have been expected would have interaction and support from charities and third sector organisations relevant to the illness, disease or requirements of care, simply did not. One participant explained:

Natalie: Obviously I knew Macmillan and [local hospice] and everything were out there, but I didn't fully understand what roles they would take and because we were never offered any help then I never asked for any.

Myself: So did you never really have any contact with Macmillan or -?

Natalie: I had no contact whatsoever. They never – and really because the year before I lost Mum, I had to have the hysterectomy because of cancer.

In her situation Natalie would have had an increased need for support from charities as she was not only caring for her mother who had breast cancer, but she was also diagnosed and subsequently treated for the presence of cancer herself. Participants suggested that there could be an expectation that they themselves were the ones who had to seek out the support of charities, all the while being expected to continue their care duties. The lack of signposting or referral was surprising to the carers in hindsight, given the size and seeming ubiquity of health-related charities.

5.6 Conclusion

The personal and professional interactions connected with the treatment of loved ones formed a highly significant part of the accounts of participants. Contact with healthcare professionals and the NHS led to a variety of experiences. For those that received comparatively good care and were able to afford their loved one a “good death” it was notable that the descriptions were brief. The expectation of a particular standard of care is widespread. Therefore, for those who experienced failings, this could be of prolonged consideration. The impact on their subsequent grief led to challenges and additional anguish as was notable just in the emotional ways in which they described the events.

The accounts described highlight that attempting to secure and access appropriate care from a disempowered position can be a struggle. For those from the most disadvantaged backgrounds, their perceived chaotic or ‘troubled’ lifestyles may have stigmatised them, their loved one and their family friends. Differences in access to treatment and support, and therefore a ‘good death’, were significantly hindered for participants such as Sheila, whose account of her struggles to obtain an initial diagnosis and then adequate care, were traumatic and damaging. Feelings of doubt, stupidity

and inadequacy were suggested as arising from interactions with those they were different from (e.g. doctors, council staff). This led to symbolic violence solidifying the view that those from disadvantaged backgrounds are on an unequal footing.

From the accounts given by participants the dissimilarities in experience arise from their ability to display capital and access discourse, that allows the social and cultural distance to be minimised those seeking assistance, and those professionals who provide it. Being able to ask the right questions and displaying the right knowledge (perceived superiority of medical knowledge over lay expertise), lack of communication by professionals (particularly at end of life stage), the need to conform to the norm of institutions (hospices), required skills and knowledge to navigate the systems (including making complaints) and, when these norms are violated or a misstep is made of normative ways of doing, the sanctions that are imposed are damaging and stigmatising.

Engaging with other agencies, organisations and authorities relating to dying and death also resulted in a variety of outcomes. For some there could be upset and anger that official bureaucracy leads to assumptions at a time when their lives are in acute crisis. The systematic inequality faced by Ian, Pamela and Sheila (and others to a lesser extent) cannot be overlooked as an insignificant determinant of their life experiences. Whilst in their accounts they did not describe themselves as poor or living in deprivation, this does not detract from the stories they told that were often characterised by difficulty, constraint and limitation. It has been found elsewhere similarly that those who are poor or deprived do often not identify themselves as being so (Savage *et al.*, 2015), and may actively distance themselves from those they perceive are poor (Macdonald and Shildrick, 2013). Structural constraints shaped their lives, their ability to provide care, their interactions with professionals and authority, and their subsequent experience of bereavement. Yet, conversely, arrangements of appropriate funeral practices could provide some positivity at an upsetting time.

While it was rarely captured in the recorded interviews themselves, several participants told me how their impetus to take part was motivated by a determination to share their experiences in the hope that them being listened to, documented and shared might avoid those in similar circumstances from going through the same difficulties they did. This was often discussed when arranging an interview, or when leaving their home at the end of an interview. The interactions with professional persons and bodies had a lasting impact and left some with a sense of injustice that they hoped could be eased by contributing to the research process.

Chapter 6: Death Rituals and “Unusual” Practices

6.1 Introduction

The previous chapters highlighted the way in which loss could be viewed as leading to a period of liminality and adjustment in the lives of participant carers, and also the manner in which the carer experience of relating to and with professionals and organisations was differentiated amongst those in the sample. This chapter aims to describe and explore the manner in which post-death rituals provide examples of similarity and contrast amongst those interviewed.

Death ritual can be a somewhat unanticipated phenomenon that individuals usually only encounter by virtue of losing a loved one. Where terms like grief and bereavement refer to the inner and private emotions associated with death, death ritual is described as the outward or public displays of memorialisation or mourning (Hockey, 2001). Societal norms shape, dominate and govern the ritual of memorialisation. This chapter will highlight some of the ways those rituals are enacted publicly (e.g. the funeral) or privately (e.g. retaining or scattering ashes) and the variations to ‘normal’ practice which can leave some carers or mourners feeling odd or isolated.

As described and highlighted in previous chapters there is evidence that suggests those from lower socio-economic backgrounds presented with a more complicated set of bereavement circumstances. The difficulty in adjusting to their new situation post death is often evident in their desire to make funeral practices or memorial meaningful. This may lead to participants seeking personalised forms of remembrance. Yet approaches that are innovative and new may be regarded with suspicion by many and seen as breaching norms of acceptability and taste by wider society.

6.2 Funeral Rituals

In experiencing the death of the person for whom they cared, all participants were faced with the organisation of and attendance at the funeral. All participants had, what might be considered a traditional funeral, with involvement of a funeral director, a cremation or burial, and a service or wake. There were no examples in this sample of completely do-it-yourself

funerals, and few woodland burials (n=2), which have increased in number in recent years (Clayden and Dixon, 2007). Often the funeral had a great deal of involvement from, or had been primarily organised, by the participant. This could be due to the nature of their previous care role preceding the death, which meant they often knew intimately what was required or preferred for the funeral, as well as there being an expectation from other family and friends that they would take the lead in death, as they had taken the lead in caring during life.

Given the pivotal role which most participants played in the funeral arrangements they were uniquely placed to give a retrospective account of the immediate post-death events. These reflections help to give a picture of similarities and contrasts in how, where and why decisions are taken with regard to funerals and memorial services.

Historically, traditional working-class funeral practice involved the keeping of the body of the deceased in the home. This was linked to the high cost associated with undertakers' services in the 1800s, so the working class would tend to keep the body of the deceased in the home, in the days preceding the funeral itself (Allen, 2007). A funeral entirely handled by the undertakers was seen as the preserve of the affluent.

Contemporary approaches to funeral services and rituals have changed however, such that this practice would now be seen as highly unusual. In the 21st century this has changed for a number of reasons, including lower premature death rates and infant mortality, housing styles that do not easily accommodate a space for the deceased, increased normalisation of funeral directors. In addition, it is perceived to be the norm for individuals to go through their lives without ever having to see or encounter a dead body, as its handling has been sequestered by the professionalised funeral directory industry (Elias, 1985; Hockey, Komaromy and Woodthorpe, 2010). This issue was highlighted by the actions of a particular participant who resisted the privatisation of the corpse. Mary took the decision to have the body of her mother at home.

Everyone was mortified when we said we're having her home. (Mary)

When she said 'everyone', that included friends and family members. Yet this was a decision that Mary took as she felt it was not morally right to do otherwise.

But we had her home and that might sound morbid to you, but I always promised her she'd come home, so we had her home. We had the undertaker come talked to us. She wanted a closed coffin, she didn't want anybody to see her, so we had her home [...] She sat there watched the telly, we had the coffin there, all the kids come, tied ribbons on it, all said their goodbye – it was lovely. The funeral director said "It was like in the old days, where they had them in the parlour". (Mary)

Mary felt a weight of expectation to explain her unusual choice, despite it being something that brought her a great comfort at a time of acute loss and upset.

People shouldn't have to justify why they do things without - but people do think you're odd. (Mary)

This view was shared at another point in the interview by her husband:

A lot of people – we're not queer, but a lot of people think we were queer cause we laid her out in here. (Stan)

Western societal suggest that death and death ritual has been secularised (Mellor, 1993). There was a notable absence of religious reference or language used by participants. In interactions with funeral directors a secular approach was not questioned. As discussed in the previous chapter, participants reflected on their interactions with funeral directors as being largely positive. Helen and her family were surprised and heartened when the funeral director arranged to have the cortege visit the Middlesbrough football club stadium on the journey to the funeral.

The funeral place, I asked could we drive past the Boro [colloquialism for Middlesbrough football club] ground instead of going the same way to the crematorium and we actually done a tour round the Boro – they opened the gates and they all stood. Aww, it was so emotional, but it made me so – I just thought, “Oh my – he would be so honoured to have all these Boro people like standing there.” [Both she and I start to get emotional and get tissues] I know, and we all had red – we wore red and white and it was like, it felt like he was watching down thinking “God, I can’t believe they’re doing this for me”. (Helen)

The accommodation of individual wishes meant that the funeral could memorialise the father of the family in a way that would be deemed to be fitting and ideal. This could be facilitated whilst still adhering to the conventional structure of a funeral procession.

Within contemporary British society, the funeral and the practices that surround death follow fairly conservative and traditional norms, often shaped by notions of etiquette. Arguably, this is changing as attitudes towards memorialisation and the funeral adapt to differing trends (Bailey and Walter, 2016). When Pamela lost her 23 year-old son, Luke she described how much it meant for the funeral directors to be accommodating of their wishes:

My husband doesn’t believe in God n’t that, and he wouldn’t have a priest n’ everything there. He took Luke in that big white van [motions to Transit van parked outside], believe it or not. [...] We had to pay for the funeral n’ everything still, n’ we had to pay for the hearse, but Roy wanted to take Luke in that van. So the man, Adam, they called him, we got a bit close to him – well, not close but he was – he was lovely, he couldn’t do anything else for us. [...] Luke’s mates all carried him, but the men had to be there, just in ca – it’s health and safety, n’ everything, as you know [...] N’ the other man stood and he talked – we wrote – he said “Tell me what you want

*me to write – err, to say”, and I wrote a thing, n’they did all the funeral for us, there was no vicar or anything. So it was quite personal, if you know what I mean? Of course, it was all young kids. I mean, even Keith that funeral man, he was crying. It was that **personal**, if you know what I mean?*

(Pamela)

In sharing their accounts both Helen and Pamela spoke with a level of surprise that the funeral directors were willing and able to assist and alter practices to suit the family’s wishes.

It may be viewed that society is at the nexus of transformation in attitudes. As such the spectre of new, different or even abnormal practice can be challenging. If it is the case that there is innovation, the accounts of some participants highlight that this is not without problems and complications, particularly in a non-religious ceremony. Helen found that attempting to provide family details for the ceremony leader to use in conducting the service caused confusion. It was to be separate from the family eulogy, which was problematic and raised issues within the family.

That was awful because y’know when – you have to do a eulogy, but get the lady to do it, n’m my brother, errm, wanted to – was quite selfish and – the awkward one – and wanted to put a lot about his family and what experiences my Dad had had with them, and I said “It’s not about each individual, it’s about our Dad in a whole” n’plus my older brother was gonna do a speech anyway, so [...] I said “This was about our Dad, but if you had any personal tributes you should’ve rang Jack [older brother] and he would’ve put ‘em in his bit”.

(Helen)

The lack of a set ritual highlighted problems around demarcation of where it was appropriate within the funeral ceremony to make personal tributes and complicated pre-existing familial discord. As previously explored in Chapter Four, family relations can have an impact on many aspects of the end-of-life and bereavement process.

Linda, when organising the funeral of her mother also experienced difficulties around the notion of perceived custom. In previous eras it was understood that the principal funeral car would transport the closest family members, which conveys the hierarchy of importance and proximity to the deceased.

One of the things that I found really hard was an issue being brought up about who was sitting in which car going to the funeral. 'Cause a family member wasn't happy that Owen [then partner] would be sitting in the car – the first car with me, even though he's my supporting partner and my brother was gonna sit in the second car with my children. But when I looked on etiquette that's the way it's supposed to be anyway. I mean he walked behind them going into the church and then joined me. (Linda)

Whilst Linda defended her choice to have her then partner in the principal funeral car, other members of her family felt that this action was a breach of decorum. In attempting to defend her choice she even deferred to “etiquette” to support her choice. The notion of etiquette in this sense evokes the received wisdom and custom of convention of a traditional culture.

For George he was eager that the family which had supported and cared for his wife should take precedence in the hierarchy of seating and travel.

I made a point, I got the funeral car, I said “They're not coming in it”, I said “Myself and Judith's sister and her husband, and our Naomi [his daughter] and her husband, we're the ones that looked after her, so they're in the car” and they [other family members] didn't like that. (George)

Sheila, who was burying her son, similarly noted issues with her sister with whom she had a long history of disagreement and problems. These frictions may emerge where classic rules of order and etiquette no longer apply and in the absence of social ‘rules’, families have differing expectations of what is right and appropriate with regard to the funeral.

So, errm, like I said she umm-ed and ahh-ed about Nana going to the funeral. So his two aunties, I had to organise a lift for them in another car, but she [sister] got in the car, why [did] she get in the car? She's only his aunty, but they seemed to take over. (Sheila)

Funerals often represent an aspect of society that is intimately bound up with religious, ethnic or cultural rituals (Howarth, 2007a). Ensuring that cultural rituals are appropriate to the individual and family is of great importance. After the death of her mother Natalie described being “out of action” and entering for the first few days what could be likened to a catatonic state due to the loss. Whilst seen as an unusual response in a contemporary UK context, other cultures would find a period of extreme grief acceptable.

When Natalie “came to” it was two days before the funeral and many of the arrangements had been made by her siblings who were less close.

The music at the funeral, I said “Well, what have you chosen?” and they said “Oh, well, we’ve chosen Elvis Presley”, I said “Mam can’t stand Elvis Presley”, I said “It was Cliff Richard she liked”, “Oh, was it?” I said “Yea” – we’d already discussed funeral arrangements and things, I said “No, she wants Unchained Melody and Celine Dion” I said “And what hymns she wanted? Yers haven’t got a clue”. (Natalie)

Her siblings had arranged a Christian ceremony to which Natalie responded “she didn’t have a religious bone in her body”. So alternative arrangements had to be made. Natalie was fervent regarding this as she wanted to ensure that her mother’s wishes were respected. This was important to many, as would be expected, however it was notable that a number of participants described the obstacles they had to overcome to achieve the ideal funeral service.

Death and the rituals related to bereavement meant that some participants had particular expectations of friends and family. When these expectations were either exceeded, or not met, it gave rise to discussion from participants.

Ken found that the friends of his deceased wife had continued to be mindful of significant milestones after her death and signalled their thoughts and support at these times.

People who knew Ruth, and she had this particular circle of friends, a textile group that they had. I think that they – well, they've always been good on remembering to send a card still on her birthday and Christmas cards, y'know, with the right kind of expressions of, erm, I don't know, expressions of what? Yea, comfort, I suppose is the only word I can use.
(Ken)

These acknowledgements of loss from a wider network were a great consolation. Tom discussed having attended local clubs and activities with his wife, and how this community showed support after her death.

The Club [club for retired business and professional people] I belonged to we always had dinners twice a year and the Bridge Club we had dinner once a year, and Aileen always came with me to those events while she was able to. [...] A number of them came to the funeral and I got sympathy cards from a lot of them, yes. (Tom)

Yet Tom found that his close neighbours were less aware of his situation. He described an encounter with a neighbour who lived a few doors down from him in the local shop:

She said to me "How's Aileen?", y'know. I said "Aileen died last year". She surprisingly hadn't heard and, I mean, it was in the paper, but not everyone gets the evening paper, do they? So she obviously hadn't heard Aileen had died. Y'know, so as I say, communities move on, don't they?
(Tom)

Tom's experience of surprise was not shared by all. Joy was surprised by the outpouring from her local neighbours, some of whom she didn't know herself, but knew her husband, Frank.

[At] Frank's funeral there was loads and a lot of people that I didn't realise would've even thought about coming, to be honest with yer, but they came, y'know. It was lovely. And the cards, the cards I got, were exceptional and they all had words like "He always had time to talk to you", err and "Nothing was too much trouble to him to listen", ooh, and I just thought "He'd have loved all that, he'd have loved it, thinking he were right nice", but he'd say "They don't know me, der they?" [Both laugh]. (Joy)

The well-wishing from others gave Joy a sense of consolation in her grief knowing that he was remembered by others as a valued member of their community.

6.3 The Ashes

In the 20th century cremation increased in popularity as a method of corpse disposal and by the turn of the 21st century it was the preferred mode of funeral in the UK (Davies, 2005). Many participants had made a choice for cremation rather than burial. This was to either reflect the wishes of the deceased or to do what felt most comfortable for the family. From the accounts of the participants this was not a decision that was difficult or from which any particular disagreement arose. However, deciding what to do with the ashes thereafter was more problematic for some participants.

Decisions on what to do with the remaining ashes of a loved one could be made problematic by other factors. Due to sexual abuse experienced as a child from her father (now deceased), Mary had reservations about where the ashes of her mother should be scattered.

Mary: I don't wanna sprinkle her in the garden of remembrance where he is [father].

Me: Oh really?

Mary: Somebody said to me, y'know, about ma history "Why don't you sprinkle her where he is" - No. But then somebody

else said the other, "Well she loved him, so you should" and I think, well, maybe I should, but I don't want to, so...

Me: But you've got to do -

Mary: What I feel is right.

Mary talked throughout interviews about the difficult balance between doing what felt "right" for her in her memorial choices and bereavement, and managing the expectations and opinions of others about what was appropriate. There was not an obvious place that she and her family felt was a suitable location for the ashes and as such we discussed this in each interview. Mary referred to "still" having not decided what to do nearly two years after the death, yet being aware that she would have to make a decision at some point.

Mary: She's still in the front room.

Myself: I was gonna ask about that.

Mary: Yea, she is. It's not sick is it? Is it? Are there any people [other than myself who do this]?

Myself: Yea.

Mary: They've still got them? I mean, I think it's just 'cause we don't know what to do that she's – that we've still got her, I mean. I dunno.

Myself: 'Cause I was gonna ask, 'cause there was a couple of times – the last time, I think probably the first time I spoke to you as well, you said a few times "It's not morbid, it's not morbid".

Mary: No I don't think it is.

Myself: Do you think other people think that it is?

Mary: Yes.

Myself: *Der yer?*

Mary: *Yes. Oh I think they do, because like I think some of the family think it's a bit odd.*

Whilst Mary felt comfortable that she should not have to do anything against her wishes, she understood that this meant she was viewed as being different. This was of concern to her.

Natalie had a different experience with regards to the ashes of her mother. After having suffered an acute “panic attack” whilst in a police station reporting her sister for fraud (discussed in previous chapter), she was referred to a mental health crisis team who visited her at home. She discussed part of their advice.

Natalie: I know it's gonna be difficult now that I am on that road [being treated for mental health problems], because the next thing is I've still got Mum's ashes [...] N'it's been – y'see I've been more than happy with – I moved her from the front room that's – cause I had her on the shelf, n'they said “No, by all means have a photograph of her because that'll fetch up so many memories of so many different things”, they said “But having her ashes there, yer just look n'it's death”, they said “So get them out the room now”. So I've put Mum upstairs for now.

Myself: *So how did that make yer feel?*

Natalie: Oh, I broke my heart. I felt like I was pushin' her out, n'I wanted her with me, n'they said “That's just – that's leftovers it's just – it's us [the bereaved] that want them [the deceased]”. Not Mum, it's us needing them. I still look in the corner where they used to be. That's my need – it's not Mum's need.

Thus despite the fact that she herself was “more than happy” to live alongside the ashes, mental health workers had made it clear to Natalie that her actions were not appropriate. The instructions of the mental health

workers indicated that her keeping of the ashes in the room was abnormal, however this is not necessarily in keeping with the known academic and clinical research in this area, as will be discussed further in the discussion chapter.

During the first interview with Natalie she had referred comfortably to her mother's ashes being situated in the living room and had not suggested that there was any pressure for her to do so otherwise. Yet in the subsequent interview she spoke at length about the turmoil over issues regarding the circumstances of her mother's death, and the following arguments with and legal proceedings against her siblings. Clearly these exchanges contributed to Natalie's stress and mental health issues, arguably more so than the placement of her mother's ashes.

Helen also experienced problems over the disposal of ashes. After dividing the ashes amongst family members Helen herself had not decided fully what to do with her portion of the ashes. This decision was further complicated by the prospect of having to sell her parents' family home.

But I can't let go, I can't – I don't know it's like – it's strange – I feel like, again, losing the house and like the ashes is gonna be the final goodbye. (Helen)

In our second and third interview, Helen discussed a wide variety of options that she had considered and researched. These included having the ashes made into a crystal, planting a tree, scattering some, having them included in a memorial tattoo. Helen's decision will be discussed further in the following section 'Keeping Mementos'.

The decisions of what to do with ashes appeared to be less problematic for some. Both Linda and Tom described their decision making with regards to the remains of their loved one in ways that did not convey any hesitancy, issues or questioning.

Aileen was cremated and a few months after the funeral the two lads n'l – cause the daughter was not very well at the time – went back to Bangor, North Wales, where my wife

came from and scattered her ashes into the Menai Straits off Bangor Pier. She always talked about walking down Bangor Pier so we thought that was an appropriate [venue] – rather than somewhere local. Y’know, we thought it’d be appropriate to go back there. (Tom)

Certainty and security in the decision taken by those who were more affluent or middle class could highlight that their personal choice was in line with societal norms. These norms guide and suggest what should be done with the remains of the deceased. Whilst these norms are not fixed or rigid, and do change, they demarcate those who have chosen conventional and traditional methods against those that have not. For those that have not they may be aware of this difference, it may not change their feelings towards it, but it is viewed as a marker of taste. It may help situate why for some the choice of non-traditional methods of keeping or distributing the ashes of their loved one felt that they had to justify these choices. Whether or not these justifications come about from direct challenges from family or friends, or whether they perceive themselves to be outside of the norm, their attempts to account for and justify were simply not present in the narratives of those who were more affluent.

6.4 Tattoo

As previously described, death rituals could be difficult to decide on for some. For some participants this uncertainty could extend into how to memorialise the deceased. Participants described a range of ways in which they attempted to remember those whom had died. For Pamela, the precedent for how she would memorialise her mother had been set with previous bereavements. She had three memorial tattoos and it led to a particular expectation levelled at her from her mother before she died.

*Cause she always said “Yea, n’yer’ll take bloody years to get it [tattoo] on, won’t yer?” Cause we always had a daft joke, I said “Nope”, I said “Before I lay you to rest, that’ll be on”.
Died [...] on the Friday, on the Monday I was sat having that*

[...] I always said "I'll have yer on, before yer in yer box, I'll have you on, Pet".

Whilst nearly one in five of the UK population now has at least one tattoo (Jordan, 2015), they are often still strongly associated with markers of taste and cultural differentiation. For Pamela (and other participants) tattoos were normalised in her family, her husband and one of her daughters having many too. Despite this she didn't get the reaction that one might expect:

Pamela: My daughters [...] went mad cause I got that [Tattoo on wrist: Figure 2].

Myself: Why?

Pamela: 'Cause they said "Ladies shouldn't have them on their arms". [...] I can't have none on my arms, 'cause I'd be a butch mother.

Figure 2: Pamela's Tattoo



Whilst tattoos may be increasing in popularity in wider society that does not necessarily mean that they are viewed in the same manner within families. For Pamela the judgement from her daughters was that her memorial tattoo was not in itself problematic, but the placement was not 'lady like'.

Pamela was not the only one in her family to have memorial tattoos and she described how her husband, Roy, also had one to commemorate the loss of their son.

Pamela: *Roy used Luke's ashes in...*

Myself: *Did he?*

Pamela: *In the – the man put it in his ink. He put it in his ink – Did Roy show you his one? He’s got a big one of Luke on his belly here [motions to abdomen] and he actually – we took some ashes and he put them in the ink and he’s on. I didn’t do that ‘cause I didn’t want that. But that’s what Roy felt he needed, and he’s used his ashes in the ink. Cause I was – “Yer can’t do that” and we asked the tattoo guy and he said “Yea, yea, bring me a tiny pinch” and they grinded it down, put it in the ink and he. But that’s real personal sort of thing cause yer know he’s there.*

Whilst Pamela had not had the ashes of her son used in her tattoo she described it as being a personal choice: “It was right for Roy, but it wasn’t right for me”. But she was understanding that it helped to bring comfort to her husband in his grief. Roy joined the discussion in several interviews and reflected on his tattoo.

Everywhere I go, he’s with me. (Roy)

When Roy showed the tattoo in memorial of his son, he took great pride in it. Both found these tattoos to be of great comfort to them and Pamela talked in detail of how she had them and when. Reflecting, she noted:

*They’re mine, they’re not for anyone else, they’re for me.
(Pamela)*

Whilst Pamela was the only participant who had (or disclosed in the interviews as having) a memorial tattoo, it had also been a consideration for Helen that she might at some point also get a tattoo. Helen suggested she had thought about it frequently, and stated she would use the ashes of her deceased father in the ink if she went through with it.

6.5 Keeping Mementos

The manner in which memorialisation was approached or undertaken, was - as would be expected - greatly influenced *by* and exerted influence *on* people’s experience of grief and bereavement. The range of items, methods

of memorialisation, and the manner in which participants interacted with an item varied considerably.

It could be difficult to know what to do for the best with regards to memorial, for some. Joy kept a card [Figure 3] on a sideboard in her living room that had particular sentimental value. The card had been bought by her husband Frank in preparation for her birthday, shortly before he passed away . He hid the card in a cupboard prior to the occasion. Frank died suddenly before he was ever able to write in the card, or give it to Joy.

Figure 3. Joy's Card



After the death of Frank, Joy found the card whilst she was sorting through items and was very touched by it.

I can't take it down, because for all he didn't write in it because, of course it happened too early, the words are just so lovely and it must have taken him a long time to find it, to have the words in that are in it, you know. (Joy)

Joy made reference to the card the first time I made contact with her on the telephone to arrange the interview and then each time we met. It was a display not only of comfort and consolation, but also signified concern for her.

And, I just – I'll take it down at some point, I suppose. But at the moment I don't feel I want to. It's, err, it's queer. (Joy)

Joy's explanation indicated that this was something that she derived comfort from, yet would describe the display as "queer". She happily allowed me to not only see and read the verses of the card, but to also take pictures in order that I could better share her experience. The poem in the card is included in the appendice (Appendix 9).

For Joy the memento of the card, alongside a picture and other trinkets related to her late husband, symbolised the life they shared together. These mementos sat together on a sideboard in her living room. They were in her home and private domain and they brought her comfort. So it was curious that Joy expressed concern on several occasions related to how wider society might perceive her.

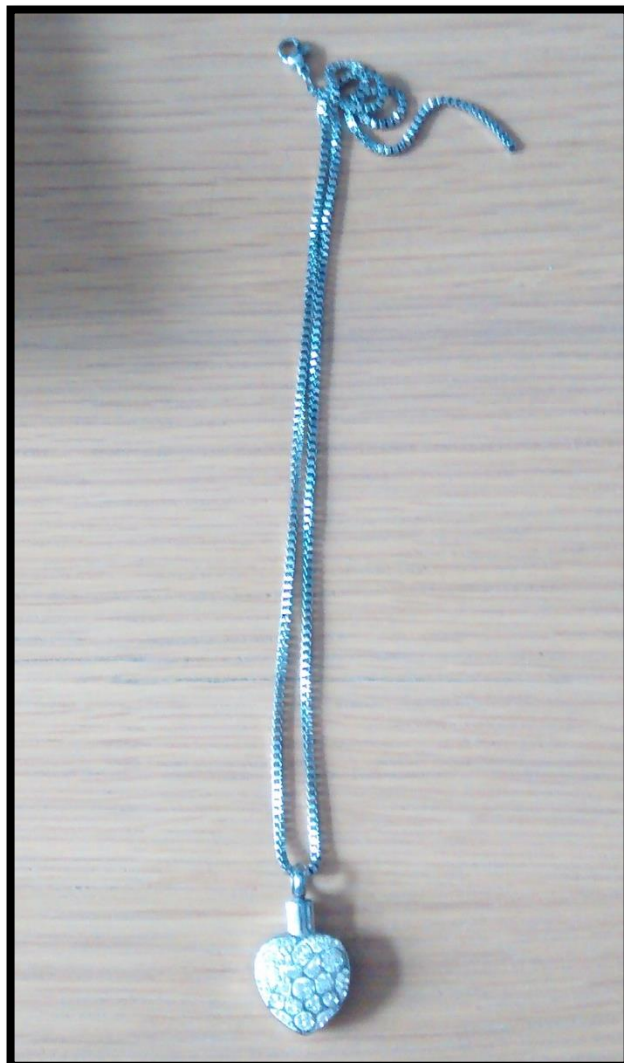
The worst part really is going to bed at night, errm, because he always give me a hug and a kiss goodnight, and err, of course, that's – that feelings never gone, I stand in front of the photograph there saying, err, "I love yer" n'all this, y'know, so I still talk to him, n'my daughters saying – I said "I think I'm going round the twist", she said "You're not, mother, just carry on", she said "It's doing nobody any harm", n'she said "If you feel that way, that's alright". (Joy)

This concern was particularly that people may make judgements regarding her mental health, her capacity, and her "doing grief". The reassurance from her daughter was of great help, yet Joy continued to feel that she was, or

could be perceived by others, as doing something that could be construed as her “going round the twist”. In being seen to be doing bereavement in a way which is wrong, she feels she falls risk of being judged to be abnormal, and potentially pathological.

These concerns can precede and inform the decision-making process related to remembrance of a loved one. As discussed previously Helen had struggled to know what to do with the ashes of her father. Once she had portioned and split up the ashes between family members she found it difficult to know what to do with her portion of the remains. After searching on the internet she found that she could have the ashes made into a crystal, but upon making enquiries this option was too expensive. Instead she found some urn jewellery [Figure 4] on the internet which she decided to buy.

Figure 4. Helen's Necklace



In the pendant are some of the ashes of her father. This memento was intimately bound up in her bereavement. She described the process of preparing the necklace as being particularly poignant.

Helen: *So what I did the very first one that I bought, I sat, there was nobody in the house, only me, I sat at the kitchen table and did it, right? I was trying – because sometimes with the ashes yer get quite big chunky bits, so you have to get a little stick and yer poke it in and I sat n'balled my eyes out when I did, it was horrible, it was the worst thing – this is the bad downside, but.*

Myself: *Why d'yer think it made yer feel so like – ?*

Helen: *Just because it was acceptance that this is him, he's not here, d'yer know what I mean? And it's like, yer know it's my Dad, and I'm talking to him saying – yer know like yer talk to him – saying like “Why did yer have to go” n’ “Why am I doing this? I shouldn't have to be doing this” n’stuff, but then when I'd done it and I realised how lovely it looked it sorta made me happy, tearful, but happy.*

When reflecting on the importance of this jewellery and comparing with the other memorial options she had considered she compared the making of a crystal with the ashes, to the necklace she had which was a miniature urn containing a small sample of ashes.

*Because that's expensive, it's too – [Motioning to necklace]
That's valuable itself without putting value on the money side of it, so I thought that's better. (Helen)*

At first she had mixed feelings when people commented on how attractive and pretty her necklace was. So I asked if she disclosed what was inside:

Depends, some people I do, but some people I just, like, I don't [...] I'm getting to [...] I felt embarrassed. (Helen)

This hesitation or ease around “some people” suggests that there is a concern that the choice of tribute that Helen made would not be positively or sympathetically received by all.

It's afterwards when you think “Oh, why did I say that?” or “Why did I tell them?”. But then I just think “It's too late, I've said it now”. (Helen)

Yet for Angela the decision to keep the ashes of her mother was straightforward and they were displayed on a cabinet in the corner of the living room with various trinkets. After losing her dog and bringing his ashes home she noted:

So we've got his ashes on the top of the cabinet now. Yea, so I said “That china cabinet is getting – for everybody's ashes”, I said “We're not getting any more hopefully”. (Angela)

Angela was comfortable with the cabinet, its contents and what this represented. She did not indicate that there would be any consideration of keeping the ashes out of sight, or of spreading them somewhere. This cabinet was of importance to showcase the links and mementos of those who had since died. She pointed to a handmade figure of a dog made out of old, shredded packets of Hamlet cigars, as its placement was poignant.

The little dog that's sat near me Mam's photograph, when me Dad was poorly he was in Poole hospital and apparently when he was in the rehabilitation place they used to get them to do things and make things, so I didn't know anything about this dogs that he used to make cause I lost me Dad when I was six, so I was only very young. But apparently our Wendy's told me, my Aunty Dot used to talk to the dog and get – like through to our Dad, yer know what I mean? So when I was there, she said would you like to take this dog home with yer. [Laughs] So then I was blubbering and crying about something that I hadn't known about, that me taking

flowers to her I ended up with something that me Dad had made with me.

The link to her past was of great importance to her and as such her tribute was a display of this. Attachment and interaction with items were significant, but not without their concerns for Mary.

Mary: I've got, under my pillow, I've got a brooch with me Mam's name on it and I've got this little trinket of my niece when she died five years ago, and they're under my pillow n'I give them a kiss every night, but I'm morbid, I know they're both dead, but – it's like when I change the bed, he's [husband] like "Oh, it's them flipping things under that pillow", but, no, I'm not morbid, I'm realistic, I mean, no, I think if you loved them you need to remember them and talk about them, they existed.

Myself: Do you think some people think that its healthier to –

Mary: I don't know, Stephanie.

During interviews Mary struggled to reconcile the fact that she could identify that others; her family, friends, wider society, might view her practices as "morbid", but didn't know why as they appeared intuitive choices for her.

Sometimes the acquisition of an important item that has links with the deceased family member could be contested. For Sheila getting the mobile phone that had belonged to her son was not straightforward.

Sheila: I got him the phone, [...] I said don't worry about the contract, so when he passed I let Leah keep the phone, errm, because of the funeral and undertakers n'different things [...] Anyway, she got caught in the net when there's a big drugs thing going on, she went to get a bit of stuff and she got caught, so the bobbies [police] took the phone off her, the bobbies had this phone 2 year.

Me: For what reason would they have it for that long?

Sheila: *Cause she'd took drugs so.*

Me: *She had – they had texts where she'd been texting 'em n'that?*

Sheila: *Yea, so they took the phone so this same meeting, that meeting when I went to – n'l said to them, I said, err, "Yea, saying that, that carry on with Marie and whoever", I said "Well, my phone, it's my phone, I told the police it was my phone" – cause they come to the house, I said "I paid the contract, I want that phone" I said "Cause nobody's been to give me it back", [Sighs] "Oh", he said "Sheila, I'll let you know", so he went back, anyway they phoned me straight away, "We've just saved it, it was just gonna be destroyed because with it being used for drugs", so it was gonna be all destroyed, so I said "I want anyone that brought it to put me phone back".*

The significance of this mobile phone was evident throughout the interview. The texts were evidence of his and her struggles, the family disputes, but most of all a link to Sheila's deceased son. A confident and strident woman in her mannerisms, she treated the phone very delicately. To be parted from it in the bereavement was difficult for Sheila.

Along with a mobile phone there were other meaningful ways in which participants had memorialised death in ways that were non-traditional. Mary had taken two videos of the coffin containing her deceased mother in the living room. During our first interview she asked her husband to show me them on their tablet. One video had no words, just music played over. The other video showed Sandra stood next to the coffin and in it she spoke:

29th August 2013, just sharing a few minutes with our Mum, it's not sad, just needed a bit of alone time - and a video to remember her by, and if there's somebody else that isn't here or is to come, they'd like to see it. Bye Mum, from Mary, Stan, especially Imogen and the family that can't be with yer

today, they'll be thinking about yer. Do you know what they're doing, Mum? Imogen's gonna throw flowers over the side of the ship, you'd like that, wouldn't yer? (Mary)

The pride that Mary took in their decision was profound. The video enhanced what otherwise would have simply been memories of that day. Mary's daughter, Imogen was on a cruise at the time of the funeral and the reference above was to her. Therefore this also allowed for Mary to share this with family members who were unable to attend the funeral at a later point. But she did feel that she had one regret with regards to the funeral:

Mary: But I just wish I'd have videoed, cause all the grandson's n'that.

Myself: Do you think that's something that might happen?

Mary: Yes, I think it will [...] They say yer video yer weddings, yer christenings, so why don't yer video a funeral? And I think to myself "Yes, I wish we had, I wish we'd sort of" – because I was really proud of them all cause they were absolutely fantastic.

To have had tangible photographic or video documentation of the family carrying the coffin, and other aspects of the funeral, would have been a comfort to Mary in her loss. But as it is not widely or routinely done, the notion to do this did not occur to Mary until after the event.

6.6 Religion, Spiritualism and Superstition

End-of-life has had links to, and provokes connections to religion due to the longstanding association of the death, the afterlife and funeral rituals. Discussion of these aspects was anticipated yet the manner in which spiritualism or religion emerged in the interviews was unexpected. Given the nature of the repeat interview process, I was able to reflect and question in subsequent meetings.

Of the participants interviewed only Linda overtly stated that she had religious beliefs. She reflected on her faith, and her occupation as a religious education teacher in a secondary school.

The fact that I have faith, errm, I think that helped me tremendously, n'I don't just have a traditional Christian outlook either, because I teach about so many different religions I can see, y'know, errm, a variation of what would be a Christian approach to death. (Linda)

Being able to draw on multiple interpretations and beliefs in death and the afterlife was of comfort to Linda, despite her noting that she was not a regular church attendee.

Other participants did not themselves claim any religious affiliation or belief. Given the societal expectations of the links between death and religion this could be seen as unexpected.

In the case of Tom, his wife had been an active member of the church, in not only attending, but also volunteering for community events and clubs related to the church. However, Tom and Aileen had always been aware and respected one another's differing views, as Tom described himself as agnostic. Therefore, the funeral ceremony had been conducted in line with the religious denomination despite this outlook not being shared by Tom, to adhere to her wishes.

For Ken whose wife, Ruth had been diagnosed with an inoperable brain tumour he had reflected how both he and his wife had never been in any way spiritual or religious. Yet before she fell ill she had a dream that Ken described.

The other strange thing [...] but she did say quite early on that she had had a premonition that this was going to happen [...] She'd has this dream where she found herself sitting on a bench next to somebody or whatever and the conversation eventually "You're going to get ill and you won't get over it". So she'd somehow had this whatever it might

have been and it was very clear in her mind that she'd had this premonition and therefore in some respects it apparently made it easier for her to bear because she knew it was going to happen, she knew it was inevitable, she knew it was going to be terminal. But I don't know how you weigh that up with any medical or factual reasoning. (Ken)

The premonition had been confusing for the family and “difficult to come to terms with”. Yet, in that it brought his wife a level of acceptance and ease in her illness, he was able to see that it was not a problematic abnormality.

For other participants the notion of spiritualism or an afterlife was something which they had subsequently become interested in. Helen stated that she was often hopeful that she would have some sort of spiritual contact and had been describing an odd event which led her to reflect:

For me I'm always looking for signs from my Dad to say – or my friend who passed away as well, or y'know different people – to say like “Away give us a clue”. But yer don't see the obvious but when something [...] happens yer just think “It's a bit strange”. (Helen)

Several participants stated that they had or were considering seeking out a consultation from a medium, clairvoyant, or spiritualist. For Helen, her curiosity and “looking for signs” had prompted her to arrange to go to a tarot card reader and also a clairvoyant.

Helen: *I'm like on the shelf with it all.*

Myself: *So do you think it will be –*

Helen: *Hoping.*

Myself: *Yea, are you hoping for something nice?*

Helen: *Yea, yea, but then I'll be disappointed if it's nothing, y'see or hear anything, but I do get reward out of if somebody else says “Eee, he said so-n-so, so-n-so and that*

was spot on” and then I think it’s people who yer know personally so they can’t lie, can they?

The experience of her friends and family gave Helen impetus to explore this further herself, and also gave her a sense of validation from their positive encounters. The mutual introduction to spiritualism was also how Joy decided to attend a local spiritualist church.

I went with, err, the two ladies I met, Gail and Norma, she said “We’re going to the spiritualist church now and again on a Wednesday afternoon”, I said “Oh, that’s interesting, like”, cause I do believe there’s something, y’know, other than what we’ve got here. (Joy)

It appeared that these encounters are not always insightful or resonant and can lead to disappointment. Joy described in the final interview how she had been several times in the period over which I had been meeting with her and had mixed experiences. On two occasions she was not particularly impressed; however she recounted the last time she had been to me.

Joy: Anyway when we went again and this was the best one for me, he was a young lad and he can’t have been any more than about 25, and right tall, right nice looking as well, n’he come over n’he said “Can I speak to yer?”, so I said “Yes”, he said, errm, “There’s somebody” he said “Has been trying to tell yer that everything’s gonna be alright” he said – again, he said “He isn’t a right tall man” he said “But he has dark wavy hair” he said “And I’ve been told to tell yer, that he’s waiting for yer and we’re going dancing as soon as yer come”. Well that – that did me.

Myself: [A little emotional] Eee my God. Yea, cause that’s what you did.

Joy: Mmm. And that was the last time I went.

Myself: How did that make yer feel?

Joy: *Well, I thought to myself "They don't know me from Adam" [...] So nobody could've told 'em anything y'know and that's why I never say anything, I just sit there and let them get on with it but as soon as he said – I must have had a smile across my face, I musta done because that's what we did and we liked doing it, we loved dancing y'know, and that's what he said "Y'alight" he said "He'll be here, he's waiting to go dancing again". So that was good, that was really good. [...]*

Myself: *And does that bring you a bit of comfort almost, der yer think?*

Joy: *Yea, yea, I do.*

However, where proclamations represent what appears to be an accurate portrayal of personal insight these are highly valued.

This feeling of connection and its importance was referenced by other participants also. Pamela discussed her experience with psychics very early in our first interview.

Pamela: *Do you believe in psychics and everything?*

Myself: *I'm undecided.*

Pamela: *Well, I was that til I lost ma son. I lost ma son 14 months previous to ma Mam, and I went to see somebody, and I believe he came to me. So of course, I had to go with ma Ma, so I went and the gentleman picked me out – and like Mam was in a wheelchair and Dad always stood behind Mam and the wheelchair with his arms round 'er, and he said, "Got this lady, she's sat down" – he didn't mention a wheelchair – he said "She's sat down", he says "Very, very, really tall man behind 'er with his arms round 'er" – and that was me, I was just phwoar, it's me Mam, I know it's me Mam [...] He says, err, "She said she's sorry she had to go, but it*

was time to go, it was time, she had to go”, and that just made me so happ – not happy, but relieved inside. And I believe that Mam’s with Dad now and no matter what anybody says, that’s what I believe and that’s how I cope. It’s how I cope.

After the death of her father, 23-year-old son and mother, Pamela found that visiting a psychic gave her some solace. The comfort she received was not without its concerns as later in the interview she discussed it further.

Pamela: I said “See, Luke’s there, he’s looking after her” – well, Mam’s gonna look after him, and that’s, you’re gonna think I’m absolutely dumb.

Myself: Oh no. Not at all.

Pamela: But that’s what I think, me Mam’s with my Dad, Luke’s still floating, he’s seeing what’s about first. [Chuckles] N’ma Mam’ll be there keeping an eye on him. But the time’ll come. [Begins to cry]

For Pamela the descriptions of her family members were incredibly pertinent to the losses she had experienced, yet she was still concerned that she might be perceived as “dumb”. It was a belief she had strong feelings towards, but was worried of the opinion of others.

In the case of Mary, she appeared to be conflicted in her attitude towards the afterlife, and phenomenon of a spiritual nature. She discussed her expectation that her Mam would come back and visit her.

Myself: Are you quite a spiritual person?

Mary: I think I am, Darlin’. I wouldn’t go to – I haven’t had me palm read or anything. [...] Where I go for coffee, on Wednesday night this week they’ve got a clairvoyant there, and I nearly rang my sister up and said “Der yer fancy going?” [...] I don’t think I would’ve gone, but...

Myself: You were sort of tempted?

Mary: *Yea, yea. No, I haven't ever been but I am – yea, I would like to think there was sommat on the other side.*

Myself: *Do you think it would – the idea – it would bring you comfort?*

Mary: *Oh, I dunno. Cause I don't wanna go – I don't wanna meet him [father that sexually abused her as a child] in the next life, y'know what I mean? I hope he's burning in hell, so y'know, so no. I think I've come to think that you just go to sleep and that's it, and it's only the people left behind that remember yer, you'd just, y'know. Does that sound morbid? Yer just gone. [...] I like the idea, but I don't [believe] – if I was to be really honest, I don't think.*

It appeared that Mary wanted to think that there was an afterlife when she considered her mother, yet when she began to discuss the implications that it would potentially mean a potential afterlife for her father also it left her conflicted and frustrated.

Beyond this there were comments from some participants that suggested a belief in fate and destiny, or awareness and choice. For some this suggestion was regarding the timing or nature in which the point the loved one died occurred. Angela described the mixed emotions she had regarding the timing of her mother's death. She had been providing care for her mother in her own home for many years, and had planned a holiday with her husband which her mother was too frail to join them on. Angela had organised respite care for her mother that week when she suddenly fell ill and died whilst she was helping her in the bathroom.

Angela: *I just knew that moment. But it was a nice way for the two of us, I think, cause she went and we had our arms round one another with the situation being as it was. [Begins to cry] That's how I look at it, and it couldn't'a been – y'know, if I'd have gone away, I dunno how I'd've lived with that. But they say things happen the way they happen for a reason.*

And then I sometimes when I think about it now, did she know? Did she know that she was going in the home and did she know that was the morning? I don't know, I honestly don't know. N'then I'm thinking to myself, well I'm glad, Greg [husband] was home when it happened, and did she realise I wasn't gonna be on me own? I don't know. Y'know the way it happened and how it had to be that day.

Myself: Does it make yer feel almost – not supersititous, but der yer know what I mean, when you say that these things happen for a reason?

Angela: Yea, yea, a reason, yea, did she know that and didn't want me to be on my own, I don't know. Cause any other Monday morning Greg would've gone back to work as normal.

Trying to understand the sudden death of her mother had played on Angela's mind for some time. An autopsy was carried out and Angela had been provided with a medical explanation for the sudden nature of her mother's death. Yet it had clearly not quite answered the questions around the timing, which seemed to be beyond justification.

The timing of death also seemed to provide Linda with some thoughts when reflecting on the final moments of her husband, Eric, who was being treated in hospital. She had just returned from saying goodbye to Eric's son, Dylan who had been to visit.

I was walking back in [hospital ward]. I was discussing him coming home, n'me brother-in-law came, n'he said "Linda, I think yer better come his breathing's changed", n'I went in the room and [...] they were checking his pulse n'that, but I think he was dead, it was his last breaths. But my Mac [Macmillan] nurse said "There's literature about how people choose when they die", n'she thinks he probably chose to die while I was out the room. [...] As I say his son had gone out

the room, Eric probably passed away when Dylan [son] went out the room because he knew Dylan wouldn't'a been able to stand it seeing him dead, not so much me, probably. (Linda)

Linda suggests that if Eric was able to control or choose of time of death, that it would have been enacted at a point that protected those he loved from the very final moments.

The notion that the person who is dying may have some influence or choice was one that seemed to raise thoughts and questions for participants. Mary's elderly mother had suffered a seizure and been admitted to hospital, after requesting that the medical staff no longer attempt to keep her alive, Mary thought that she would die peacefully and swiftly. However, her mother continued to have seizures frequently over a nearly 24 hour period that were very traumatic for the family to witness. She discussed the moment when her mother passed away.

Mary: We were there all night, til – it was strange really – well, not strange knowing you mother. [Begins to cry] She loved my husband, he came in at the half past eight and she finally died at twenty to nine, I said to him "You should have come in earlier".

Myself: [Voice breaking] You're gonna make me cry now.

[We both laugh]

Mary: I can laugh about it because – we laugh because he literally walked in the door at half past 8, Stephanie, in the morning, I had hold of her hand. She didn't have any more fits and I just felt her go at twenty to nine. I said to him "You should have been here all night and she wouldn't have had to go through that", but yea, it's terrible.

In attempting to reconcile the harrowing death of her mother, there was an impression that the suffering she endured was senseless. By suggesting, in a somewhat facetious manner, that the timing of her husband's arrival would

have altered this, provided her some way of making sense of the hours of distress watching her mother die she had sustained.

Natalie's mother was conscious until the very last hours of her life. Natalie recounted how her mother asked if she could "go".

After the doctor came back in and Mum looked at me, she said "I love you", I said "I love you too", she said "I've had enough" I said "I understand that, Mum", she said "Can I go?" – [...] She said "Can I go?" and I said "You can go anytime you want", she said "Is everything okay?" I said "Everything's fine", she said, um, she said "Colin's [Natalie's partner] good", she said "I know I can leave you now", I said "Oh Mam". (Natalie)

In the way in which Natalie recounts this there was an understanding between Natalie and her mother as to what "go" was a euphemism for and what the consequences would be. Given that Natalie had provided constant care unassisted this conversation was also of great importance due to notion that her mother gave her approval and faith in Natalie's choice of partner, Colin, suggesting this meant she could die at an appropriate time.

For the participants that referenced the timings of death, there was very much a sense that this was not simply coincidence. It therefore required an interpretation on behalf of the participants to generate meaning out of a part of the lifecourse that is viewed as being difficult to predict and anticipate.

6.6.1 Difficulty of Continuing Bonds

The ways in which participants talked about spiritualism were different from their descriptions of what could be termed continuing bonds. The act of seeking out a conduit to potentially receive a message from a spiritual afterlife, should not be conflated with the manner in which participants had a lasting connection by way of talking to their deceased loved one.

Whether it was through mementos of pictures or special items, several participants discussed their continuing bond to be of great importance to

them. Despite this there were concerns about the way in which this bond might be interpreted.

Like I wouldn't go to a stranger [...] 'Oh, I sit and talk to me mam', my friends, my family I'd tell, but I wouldn't say to a stranger, I wouldn't, no - but you're just covering yourself up thinking "Oh, do they think I've lost the plot because I'm talking to someone dead". (Pamela)

All of these acts of memorialisation carried great significance for the participant. Often participants seemed fairly comfortable in describing these decisions to me as the researcher, yet when asked to reflect on what others (individuals and wider society) might make of it, their answers elicited less favourable responses.

It's all like dead channelled and you just feel like you have to go down this path and if you vary off it, 'Oooh, there's sommat wrong with them, they've got the mother in the front room, that's weird they haven't even got the curtains shut' y'know? (Mary)

The worry was sometimes based on the challenging or discomfort of friends or family in ways that could be very direct and overt. Pamela noted that this may be related to the individual with whom they are interacting:

Saying that, I've gotta a mate who yer can't talk about like Luke, and can't talk about ma Mam n' Dad in front of 'em, she will not talk about death or anything, or - yer know I'll say like "Eee, I was talking to our Luke the- " -- "Don't be saying that, it's weird" and she won't let yer have no conversation like that or anything. (Pamela)

These perceptions made it difficult for participants to explore their grief. In attempting to vocalise or express the emotions that their loss had plunged them into it seemed that wider opinion or expectation provoked a need to justify or account for their behaviour.

It would appear that whilst their actions and choices were personally satisfying and meaningful, for some participants there was risk attached. This risk was that of being shamed for the way in which they memorialised their deceased family member by the discomfort or objection of the other person. Sometimes the challenge to their behaviour was overt and direct from family members, friends and professionals. Their difficulties around both processing the shame and stigma that was conferred to them by the policing of others, whilst also wanting to have a method to memorialise that felt personally meaningful. This overt prejudice toward their choices is a form of systematic violence, that aims to alter or cease the actions and replace them with ones that are not considered deviant.

6.7 Conclusion

The accounts explored in this chapter point to a wide range of experience regarding differing approaches to funerals and their arrangements, display or disposal of ashes, the desire to seek spiritual solace or reassurance, and the ways in which participants memorialised their loss through tattoos, jewellery, and keeping of significant mementoes.

The variety of rituals and memorials highlights the multiplicity of meaningful ways in which participants creatively and actively sought out to address their grief and make their bereavement manageable through personal acts of commemoration. However, there can be a tension regarding cultural expectations of which and what funeral practice, memorialisation and bereavement are normal. The desire of participants to make meaning and explore alternatives were met with resistance. Questioning, querying and policing of bereavement behaviour could be overt, as was the case for Pamela whose family were unhappy with the placement of the memorial tattoo on her body, and for Natalie when the intervention of her mental health workers led her to move the ashes of her deceased mother to a less prominent place.

The overt and explicit violence that was perpetrated by questioning and shaming these memorialisation behaviours, could be seen to also be internalised amongst participants. It was evidenced that many participants

felt or perceived that their behaviour might invite criticism, or was in fact, proof that “there's sommat wrong with them”, “going round the twist”, or having “lost the plot”. This feeling was palpable for participants and led to them doubting their mental health and capacity. The doubt was insidious and could lead to them feeling uncertain of their actions and worry that they were abnormal. This symbolic violence could mean that whilst they wanted to have the comfort and confidence in their actions that some participants (Linda, Ken) did, it was an ongoing struggle to come to terms with it.

For some participants this could contribute to, in part, their desire to seek out others with similar views, such as attending a spiritual evening. This could be a difficult event to attend, and some participants were openly conflicted as to whether their attendance at such an event would help or hinder their grief. There can be scepticism around clairvoyance and spiritualism, and so having confirmation or positive experience from a trust source helped to see potential value in attendance to aid their grief. Potentially open and shared practices that reflected a collective discourse of acceptable approaches to grieve, could have lessened the potential stigma and helped participants resist the symbolic violence of their grief being ‘abnormal’.

Having a clearer understanding of the benefits continuing bonds as a way to grieve could help ameliorate the reluctance for some to share their thoughts, behaviour or memorialisation openly. Resisting the overt oppression of friends, family members or authority figures could pose additional gridlock in the already emotionally labour-intensive bereavement. There was no evidence that such resistance would be of personal benefit. It was also the case that participants described these worries that their deviation from a perceived norm could inscribed them as distasteful, “weird”, or indicative of having “lost the plot” regard by nature that there is a prevailing guiding norm. These feelings of doubt were more prevalent in participants wishing or willing to memorialise or continuing a connection in a manner that they felt to be out of the mainstream of accepted bereavement practice.

Chapter 7: Discussion

7.1 Introduction

The asymmetry of experience that has been outlined in the previous chapters is significant. Participants themselves often found their caring role, and then their bereavement, deeply personal and, at times, isolating. This speaks to not only the suggestion that death has been sequestered (Timmermans, 2005), but also highlights the difficulties that participants may have had relating their circumstances, interactions, and feelings to a normative standard that resonated or reflected themselves. It is important to explore further how their generous insights and the conceptual work in the wider body of sociology can help explain why it is the case that some persons struggled in their bereavement more markedly than others.

In the ordering of value, there are those who are arguably winners and losers. Those who observe the tacit rules of society, in an orderly and obedient manner will be considered virtuous. For those who find themselves navigating complex or chaotic family circumstances may find that their ability, predilection or awareness of these norms may be distanced.

An overarching theoretical framework that ties closely to one school of thought, such as that of Bourdieu, will not allow the exploration of concepts that can be utilised to make sense of an area of the lifecourse that has been often overlooked. Therefore this discussion chapter will be explicit in its use of a range of concepts and ideas from across the social sciences. The argument remains clear, however, a diversity of understandings will help paint a richer and more robust argument.

Previously I have outlined some of the rich narratives that participants of this research shared. With a wide range of themes and issues, it is important to consider these accounts in juxtaposition to the existing evidence base and sociological literature. The purpose of this chapter is threefold. Firstly, outline further analytic interpretation of the findings chapters. Secondly, relate and understand the empirical evidence presented here in relation to previous literature and concepts. Thirdly, to utilise the previous to aims to delineate the argument as arises from the research conducted.

7.2 Structural Inequality

As a researcher, it was a privilege for the accounts of the participants to be shared. Particularly with such intimate detail. It reinforced a strong belief that the work of Wright Mills (1959) is foundational here. In his now classic work *The Sociological Imagination* he made the case “that many personal troubles cannot be solved as merely as troubles, but must be understood in terms of public issues” (p. 226, *ibid*). The call is to think of ‘personal troubles’ not only as narrativized biography but to link to and place them in their wider social and historical context as ‘public issues’. Beyond this, he was an activist and advocate who believed in concerted change. His position makes vital the grounding of the isolated accounts, as presented by participants, in their wider social context relative to one another (Back, 2007). The struggles of one and the absence of similar for another is not simply difference or coincidence.

Participants in this research referenced many troubling personal problems featuring within their history or families including suicide/suicidal ideations, criminality and imprisonment, domestic abuse, childhood sexual abuse, poverty and welfare problems, unemployment and debt, housing worries, familial disputes, kinship care of family infants. These were often interwoven and integral to the narration of their care journey and grief. The cumulative nature of multiple crises, traumas or tragedies is not fully understood or appreciated. However, there is strong statistical evidence that inequality hampers social mobility and that many of the issues listed above cluster in the lives and communities of the most deprived in a society (Wilkinson and Pickett, 2010; Dorling, 2015). Latent power struggles are evident throughout the narrative accounts of participants. As part of this discussion I shall interrogate how this is the case by reflecting on the examples provided in the findings, it is important to outline the conceptual argument which underpins this interpretation and make the case that symbolic violence is a concept which needs to be considered more thoroughly in the sociology of death, dying and bereavement.

Earlier chapters have outlined a vast quantitative evidence base that suggests that inequality is an entrenched and increasing characteristic of contemporary UK. Teesside is an area with marked disadvantage as a result of years of deindustrialisation, lack of investment and austerity. Relative affluence and marked poverty are often very closely located in the towns and neighbourhoods of the region. This is the context in which participants were located. Participants in this study were not asked to categorise their class status or divulge personal financial information prior to taking part in the study. In describing their circumstances, interwoven as providing context to their experiences of caring and bereavement, it was clear that there was a spectrum of difference. Retired grammar school teacher and precariously employed cleaner are just examples of the occupations that participants in this research had. Some lived in some of the most deprived wards not only in the Teesside area but in England. The economic capital these differences highlight are foundational in providing context for the resource (or lack thereof) that different participants had to draw upon when faced with caring responsibilities or grief.

These structural differences were rarely recognised or reflected upon by participants. The accounts they gave represented a very individualised perspective, even when questions about family, friends, and wider society were posited. Some participants faced many more obstacles and hurdles than others. The consequences were not always overt in their chronicling of day-to-day care, medical interaction or funeral planning. However, their stories were often couched in and interrupted by the social, financial or familial issues that are commonplace and difficult to avoid when living in and around deprivation.

7.2.1 Symbolic Violence at End-of-Life and Bereavement

There is a reason participants are not able or willing to readily identify their personal challenges in a wider structural context. Social hierarchy as is characterised by 21st century capitalism exists in a very particular form referred to as neoliberalism. It is a function of neoliberal ideology to simultaneously withdraw state intervention whilst placing the blame for any subsequent inequality on the individual (Harvey, 2005; Peck, 2013). The

participants of this study find themselves in a context that is both complex and exclusionary. The demands of the caring role at end of life are immediate and all encompassing similarly is the bereavement that participants then had to face. Understanding their place in an unequal society was not only difficult but deliberately not encouraged. It is a very specific function that symbolic violence plays as a mechanism that whilst people are able to see themselves as having different experiences and resources from others, they are also led to believe that this is due to their personal failing or success.

As discussed in the literature review the function of the neoliberal state when applied to health and illness takes a particular logic (Ayo, 2012). Firstly, there is a withdrawal of state intervention and funding, this allows for the second phase in which wellness becomes a market, this in combination with the third aspect of the potential for ill-health to be framed as a risk, leads to the key moralising over health and illness whereby the individual is responsible for themselves through their behaviour and lifestyle choices. Finally, this allows for any arising inequality due to austerity measures and reduction in state support, to instead be deflected and attributed to the individual. As I shall see throughout this chapter, participants in this research often attributed the many challenges they faced to themselves and rarely to a wider set of social determinants. Often they would feel that their discomfort in a system or in the choices they made, were due to their own personal or situational circumstances.

Yet why is it beneficial for a society to be structurally unequal? Classificatory systems came about as an attempt to differentiate and 'other' particular groups who were then deemed problematic (Finch, 1993). This distance allows for the legitimisation of dominance and exploitation. The process through which class domination occurs may vary in different settings (e.g. paternalism, exclusivity, snobbery, victim-blaming) yet the aim is to maintain the asymmetry of power relations. The situations and accounts told by some of the participants in this research demonstrate how they present or embody difference. This is evident in multiple examples and sites, including medical interactions, choices of memorialisation, and bereavement practices.

Crucially, these practices are not considered 'different but equal'. Instead, the practices of the dominant are generally presented as exclusive or 'distinguished' whereas those of the dominated are perceived as common or 'vulgar'.

(Atkinson, 2015, p. 69)

In reflecting on the accounts provided by participants in this research the process by which the fear they have of falling foul of the norm regulates their behaviour, shows both an acknowledgement of the norm, and also how they do not conform to it. Attributing failure to the individual despite strong evidence that there are structural determinants often outside of their control can be seen as evident across many aspects of society. Particular social norms become either vilified or virtuous.

The observation of socio-economically weakened persons attributing failure and hardship to themselves and their actions is not new. Symbolic violence is a concept originally described by Bourdieu (1984) which an individual may at once be simultaneously constrained by social structures, and replicating the normative practices that allow for those very social structures. This ensures that the control over the status quo is maintained without being visible through obscuring the power relations which ensure asymmetry of authority, legitimacy and status. The effects of this are "violence which is exercised upon a social agent with his or her complicity" (Bourdieu and Wacquant, 1992, p. 167).

Yet the concept of symbolic violence does not quite extend far enough. Both Skeggs (2011) and Tyler (2015) note that the limits of understanding are that it does not account for attempts to resist or challenge the dominant values in society. Whilst resistance may not necessarily be successful in changing a power imbalance, even the act of pushing back is significant. This will be shown in the findings drawn upon in this research.

There could be a reluctance to challenge, as Bordere (2016) notes: "That marginalized groups may be less likely to resist dominant or oppressive forces [...] as needed, because the "cost of noncompliance" can be especially high" (p. 15). The concern and fear of not presenting an

acceptable facade in certain settings was something that participants in this research described, and will be further explored in this chapter. The manner in which dominant culture pervades means that those who would ordinarily fall outside of the acceptable parameters can find it challenging when necessity dictates that they should behave in a certain manner. The inhibition can lead to a lack of self-confidence, self-worth and entitlement, that more privileged counterparts may never consider consciously. Skeggs (1997) discusses how the desire to be seen as and considered respectable is a particular challenge for those who do not automatically possess a respectable position in society.

The social, cultural and symbolic chasm between different groups can lead those, who are by their very nature subjugated, to consider what is to be gained from challenging or resisting the will of the dominant. This is not necessarily the case for all. Where there is challenge or conflict it can have very damaging consequences, and usually not for the dominant, whose position is buffeted in numerous ways (e.g. culturally, legally, regulatory). This can lead to being denied access to particular settings or services, or if the behaviour is not corrected and the issue becomes irreconcilable it can seem less damaging to remove oneself from the situation. This chapter will give specific examples of this for the participants in this study.

7.2.2 Sociological Step Change for Death, Dying and Bereavement

Throughout much of the literature within the sociology of death, dying and bereavement there has been a lack of interrogation of the experience through a class-based system (Howarth, 2007b). By overlooking the effects of inequality as created by neoliberal capitalism it is very difficult to place an in-depth critique of the day-to-day experience of those living in and through some of the most challenging circumstances at end-of-life and bereavement. The gaps in the literature in this area mean that particular issues are not acknowledged and therefore run the risk as Howarth (*ibid*) describes of making “[...] unsubstantiated assumptions about the experiences of working-class people” (p. 434). To build on this the chapter will unpack some key examples that build into the argument around three key themes: *private troubles*, *power asymmetries*, and *being symbolically deviant*.

Private troubles: Addressing multiple issues and responsibilities at once could prove challenging for some participants. A complex interplay of issues such as domestic abuse, criminality, drug and substance misuse, care and kinship care of grandchildren, divorce or separation, were just some of the limiting and demanding issues that participants referenced. The social networks upon which participants were located were also problematic. Familial relationships could, in quite considerable ways, be a help or hindrance to the act of caring and memorialisation. Mitigating and managing, or opting out of doing so, of these relationships framed the boundaries against which they were able, or not, to look after the family member as they approached death, and also how, when and why they made a decision around the funeral and beyond.

Power asymmetries: In terms of entering the into institutions where a particular form of interaction is expected to take place participants again had varying resources to draw upon. Medicine as an institution is socially organised and seeks to ensure its legitimacy through meritocratic status symbols. Micro interactions where an individual presents with different cultural experiences can demonstrate sites of difference in which the participant felt themselves to be in a position that was detrimental to their desire to obtain support or relief for their unwell/deceased family member.

Being symbolically deviant: Whilst attempting to make sense of a significant loss in their life participants outlined their concern that their behaviour might deviate from a norm, or be perceived to deviate from a norm. This deviation from the norm was perceived to have potential consequences and these invoked fear. Participants were concerned with, but also in some cases resistant to, being labelled in a way that could entrench their identity in stigma. Conflict in acceptable tasteful choices or actions could be met with chastisement, correction or sanctions. This form of policing did not always feel acceptable or comfortable and could arguably have long-lasting consequences. Not everyone is able to draw understanding or evidence to reaffirm their beliefs and actions. Therefore it can not only be difficult to resist the labels of deviant, but it can perpetuate into the future where the policing of acceptable behaviour is inflicted upon others.

This chapter will now explore the findings described in the previous chapter in light of the argument above to both give examples from the accounts of the participants, and utilise the conceptual framework offered by applying a sociological gaze. Firstly, paying attention to the familial support (or lack thereof) and the multiple personal troubles they encountered, I argue that these are public issues worthy of interrogation. Secondly, in making explicit the asymmetrical power interactions that participants described I shall highlight how the use of positionality to silence is utilised. Thirdly, examples from participants narratives will give a rich display of how their bereavement was policed. All of these taken together will allow this analysis to exemplify how this is indicative of wider hierarchical class-based inequalities, and how these inequalities are surreptitiously sustained, enacted and inflicted at a time of great stress and distress in the lifecourse.

7.3 Private Troubles or/as Public Issues

Whilst this research did not seek to gather quantitative evidence it is important to note the well-documented evidence base which suggests that as the prevalence of inequality in a country increases, so too does the propensity for social problems to cluster for those who are most disadvantaged (Wilkinson and Pickett, 2010). Wealth inequality is the marker by which other social issues can be tracked. Those who find themselves in poverty are more likely to experience low levels of trust, mental health issues, low life expectancy, obesity, poor educational outcomes, homicides, suicides, imprisonment, and low social mobility (Wilkinson and Pickett, 2010). How these issues intersect with care responsibilities at end-of-life or bereavement has received very little attention previously.

In this research participants were (with occasional exceptions of partners being present) interviewed alone and asked about their experiences from their perspective. It may be somewhat unsurprising in that what resulted were accounts that were often personalised and individualised. This might seem very obvious, however, their participation in a study that looks into numerous persons' accounts might be indicative that their experience is not singular nor isolated. There were only rare instances of linking their experiences to wider structural issues. This is not merely a sign that it is not important to think of

these as isolated, but rather a call to shine light, question and explain how a neoliberal state benefits from this atomisation of understanding.

Whilst not all readily identified or felt wholly comfortable with the term, a unifying feature of all participants accounts was that they had provided physical, social and emotional support as a carer to someone who subsequently died. The responsibility of caring is not always a linear one that comes on suddenly. More often it is a slow creep of additional responsibilities that are taken on by someone as the person they love loses their independence to ill-health. The cumulative nature of care can be a challenge to adapt to. Those interviewed for this research had left employment, suspended job searches, adapted their homes, and/or moved in with their unwell family member. Not one person described these changes as anything that they resented, however, they were easier to undertake for some. Additional issues that complicated their care roles were numerous for example, Helen had wished she could spend more time with her father (and then unwell mother following her father's death), however with an alcoholic husband this was not easy.

The capacity to undertake a caring role was aided or frustrated by the resources upon which they were able (or not) to draw upon. One such resource was the family that surrounded them. For Ken and Tom the support that their immediate family was able to provide proved to aid the caring and end-of-life process and did not ever discuss lack of income as a concern. Yet for Sheila and Natalie, their family struggles led to conflict and dispute around the distribution of caring roles. The ability of some to leverage familial support in addition to relative financial stability goes some way to highlighting the cleavage in journeys of care-giving.

Complications to care were not always discrete and separate from bereavement. For Pamela and Helen, their care responsibilities and their experiences of bereavement overlapped significantly. Whilst caring for her long-term paraplegic mother Pamela had to manage the rapid onset of illness and decline of her father, and also the death by drugs and suicide of her son. At the point of interviewing she had lost her son, father and mother, yet was

providing daily care for her young grandchildren. She described the points at which caring responsibilities (for either parents or grandchildren) had put pressure on her own ability to grieve, particularly in relation to her son's traumatic death.

Helen presented a similar experience of attempting to process grief whilst also attempting to provide care. The pressures of caring for unwell family members placed her at odds with the familial expectations of her husband who, she described as having alcohol misuse issues, wanted her to remain in their home more. She felt that if pushed she would rather have cared for her mother who suffered from dementia than placate the desires of her husband whose behaviour was unpredictable. This was not necessarily a realistic option given his dependence on her for her role in their business and her domestic work, which she viewed as keeping her tied into the relationship. Alcohol misuse in this instance highlights where other challenges intersect, overlap and complicate the role of the carer, or their subsequent bereavement.

The experiences of both Pamela and Helen highlight an absence time, or in personal space, to allow for the reflexive emotional exploration of grief or juggling of care. This was not discussed as a problem that could be easily solved, but one which they shouldered day-by-day, where conditions changed and the focus was to find the path of least resistance to appease and care for all. Where they were able they found solace or support in small moments of time to ease their stresses, such as physical affection from grandchildren, or attending a local carers self-help support group. The experiences of Pamela and Helen were not the case in all accounts, particularly those who enjoyed increased financial or familial resources. Arguably those with for whom familial relations were easier or were able to financially pursue a course of self-care were better placed to attend actively to their grief and wellbeing. Linda who shared familial responsibility of care for her parents described her attempts to "cocoon" herself whilst she was bereaved following the death of her husband. This constituted paid time off work and support from her adult children to focus on her emotional labour.

Of the participants who took part in this study, it is of note that the majority of those providing care for a family member were female and many were of working age. There were three male participants in a sample of 13, which is fairly significant when taking into consideration the gendered manner in which care is viewed. Yet only one of these three men were of working age, and the other two provided care for their significant partner. This reflects evidence that suggests that women are more likely to reduce their working hours or give up work in order to provide care.

The expectations of who should provide care were mentioned by participants when discussing how responsibility for care was discussed and apportioned within the familial structures. However, they did not reflect much on the gendered nature of this. Participants would highlight how it had come to be that the responsibility for care had fallen to them and often it was to do with the perception of their resource to do so or who had the capacity (part-time or low waged work that could be given up). Those where income was tight were more likely to experience conflict around care.

Many participants did not receive carers allowance either for a long-time into their caring role, or at all. It is estimated that unpaid care saves the UK state approximately £57 billion per year (Macmillan, 2012; Gardiner *et al.*, 2014). The lack of awareness leaves a population undertaking deeply demanding physical and emotional labour invisible whilst simultaneously adding huge amounts of value to the economy in costs saved. Worries around income, bills and housing were described by Ian and Joy as provoking anxiety in the immediate post-death period. This was at a time when other participants described their experiences of arranging funerals and ways to memorialise.

Research by MacDonald and Shildrick (2013) noted that an overwhelmingly common theme in the biographical accounts of young people in Teesside was the multiplicity of pressures, constraints or challenging events that could sometimes provide the pinpoint or 'critical moment' at which their conditions deteriorated and forced action or inaction. They suggest "the force of critical moments often came from their combination with the multiple pressures on wellbeing of growing up in poor neighbourhoods" (p. 159). Their work

explores how events outside of their control (bereavement, ill-health, familial unemployment and criminality, etc) can intertwine in their accounts to explain some of the positive or negative life events or choices that have occurred in the time since. MacDonald and Shildrick argue the value of paying close consideration to these points in biographical interviews:

Through attention to the role of critical moments – whether related to ill health and bereavement or not – is one way in which researchers can avoid over-deterministic theoretical accounts of social exclusion or youth transitions, explore the agency of individuals as they actively negotiate their conditions of life and provide more convincing analyses capable of explaining individual difference in shared social and economic circumstances. (p. 157)

Participants in my own research were also giving retrospective accounts, however many of them identified themselves as still, or having yet to be, grieving. In this sense, being able to 'look back' (MacDonald and Shildrick, 2008) is more challenging when assessing the consequential impact of the bereavement in their life. Most participants suggested that their loss had a huge impact. The magnitude of a close bereavement is of little doubt.

Drawing similarities with the work of MacDonald and Shildrick (*ibid*), that suggests that this loss can compound, or be compounded by, already difficult living circumstances, may go some way to explaining the differences in dealing with grief displayed by the participants in my research. Whilst agency is a contested concept, particularly with reference to constrained socio-economic conditions, what the notion of critical moments can highlight in the light of the evidence of the work of Wilkinson and Pickett (2010) is that a clustering effect of social problems can constrain an individual or limit the scope of recourse to positively progress.

As outlined, lack of material resource or poverty is not enough to explain why some experience more social problems, as if this was the case rich countries would see less than they actually do. "What matters is where we stand in relation to others in our own society" (Wilkinson and Pickett, 2010). These

examples highlight a gulf in everyday practice. A cumulation of problems are experienced and expressed by participants of this research, such as Sheila and Pamela, who struggle in their precarious lives to care for families beset by criminality, mental ill health, and lack of opportunity. There has previously been little research to comparatively understand the lived experience of care and bereavement in communities experiencing disadvantage, this indicates a gap in knowledge.

What has become clear is that there are differences in experience as described by the participants of the research. First and foremost, the impetus is to make explicit the private troubles of participants who would otherwise have little recourse to a public platform. The aim is to then describe how these private troubles constitute public issues. The following sections will seek to add further evidence based on the findings of the research presented in previous chapters.

7.4 Medicine as Power Struggle

7.4.1 Death, Dying and its Mediators

All of the narrative accounts provided in this research included reflections on the interactions with healthcare professionals. Whilst not always prompted by myself in the interviews, for participants these incidents could shape in many ways their retrospective accounts of the ill-health and death of their family member. It should be noted that no healthcare professionals were interviewed for their perspective as part of this research. However, there is evidence to suggest that in their interaction with those that they perceive to be from a lower social class that doctors will make assumptions based on their interactions more, like their patients less, and feel less inclined to give detailed support (Pilnick and Dingwall, 2011; Morgan, 2018). Accessing healthcare was necessary, but not always easy or welcome. In this section, I shall explore the consequences of these interactions as based on the findings, and argue that these incidents can be further complicated by asymmetrical power dynamics.

To understand the accrual of power within the medical profession requires a brief long view of its origins. Biomedicine that it is a relatively recent

development at only 300 years old approximately. Prior to this, there was often those in a society whose expertise may be drawn on when disease and illness struck, whose knowledge and treatments would be based on a mixture of hearsay, tradition and observable change (Le Fanu, 2011). So even in the earlier formations of medicine, there were those who would be marked out as special and potentially given elevated status based on the accrued knowledge they had. As medicine became more scientific and technologically driven the formalising of education and apprenticeship meant that it would take many years for physicians to undertake and achieve their craft and profession (Lupton, 2006).

Today this undertaking is rewarded with professional status in society. The expectation upon patients is one of deference to professional authority and expertise. In submitting to the power of the medical realm patients may be conferred the support they require, such as access to treatment and appropriate welfare. Recently, multiple factors such as patient push for demedicalisation (Conrad, 2007; Eckhert, 2016; Yates-Doerr and Carney, 2016) and austerity tightening budgets (Schrecker and Bambra, 2015), has seen medicine slowly move from a paternalistic model of healthcare to one which promotes preventative self-care and self-management. The consequences of this lead to mixed messages for patients. Accessing healthcare in the appropriate manner at appropriate times can affect medical interactions.

Despite changes in the NHS, health inequalities are persistent, and whilst structural issues such as housing, pollution, poverty, etc are known to contribute to the continuing disparity (Graham, 2007; Dorling, 2015; Bambra, 2016) there is also evidence to suggest that the structure of healthcare and the care provided by practitioners could also be a contributing factor to the variance in health outcomes. Research suggests that those from ethnic minorities or lower socio-economic backgrounds are more likely to receive poorer care (van Ryn and Burke, 2000). When asked about favourable or preferred patients practitioners stated that those who took a more “active” approach to their consultation, for example by asking questions and providing relevant information, were more likely to be viewed as contributing to their

own healthcare (Willems *et al.*, 2005). This could lead to worrying trends in access to healthcare (Schouten and Meeuwesen, 2006) if there are latent prejudice regarding who is or is not, deserving of good healthcare based on their willingness or ability to be an active patient. Some of these struggles can be seen in the accounts of participants of this research.

7.4.2 The Consequences of Falling Short of Expectations

Perceptions of another's emotional response can be a precursor and facilitator of judgement. In conversing with healthcare professionals, the participants in this research outlined where they felt that there was an expectation upon them to interact in a particular manner or engage with discussion or questions in a way that they felt unable to. Managing themselves and their (potential) reactions at a time of heightened emotional turmoil could be testing and ultimately damaging.

Taking the incident recounted by Sheila, of the conflict over her son's wellbeing with the hospice staff, she displayed anger not only when describing what happened in the interview, but also at the time. Yet the treatment of Sheila indicated that her knowledge and expertise as a carer was not valued. She had impressed upon them that her son was unable to lie flat due to the pain, yet they deemed it necessary to attempt to contort his body in a way that had become very difficult for him. This dismissal of Sheila's instruction was tantamount to deeming her input to the care of her son worthless. Whilst initially resistant and wishing to maintain their jurisdiction of care for Carl, in relenting the point was proven that the hospice were not able or willing to cater for all needs and preferences of care and dying. The hospice wished to not only satisfy and ameliorate the upset of the family but maintain the social order of the hospice.

The social organisation of end-of-life (Sudnow, 1967) was challenged and broken by Sheila and her family. In their active management of the body of her dying son, as well as the active management of the family, the hospice clearly delineates the normative behaviours that it believes should be adhered to. Where this may have been interpreted in one light as patient-centred care, what it became was a paternalistic attempt to ascribe

appropriate ways of being. Sheila was able to recognise the manners in which she was expected to react and behave in this setting when she says that “they know best”. Yet, when it turns out that their well-intentioned actions have inflicted additional suffering onto her son, and by extension the family, she is no longer able to mediate her reaction in accordance with hospice norms and erupts in an angry outburst. The consequences of this were that Sheila demanded that he be discharged, and the family had to undertake most of the care during the final end-of-life stages. In doing so, their access to therapeutic pain management was made more difficult.

On a separate occasion Sheila described in one interview that, in terms of the treatment of his terminal cancer, she felt Carl had been judged and written off as a “drug user”. As evidence (Van Boekel *et al.*, 2015) and experience may bear out the concern of Sheila, a discussion and decision in conjunction with paramedics was taken to avoid a particular local hospital when Carl required admission again. The purpose was to avoid the stigma that Sheila worried Carl would be subject to.

Anger is an emotion that is not well tolerated (e.g. zero tolerance NHS policies), and whilst an arguably rational response in the circumstances highlighted, clearly to the carer the therapeutic relationship to be ended. Evidence suggests that Sheila and Carl could potentially be framed as ‘bad’ patient/carer (Sointu, 2017). Another participant, Ian, was similarly angry and scolded the GP for their assumption of potential poor comprehension on his part. The eventual breakdown of care and refusal for medical intervention by Ian’s uncle Nigel it is clear that when normative expectations of medical interactions are challenged or infringed the effects are little felt by the healthcare professional, but have serious repercussions for the ill.

Across several interviews were examples of poor healthcare. The consequences being, for Sheila and Ian, that healthcare was accessed in a calculated way that would minimise the potential of discriminatory and poor palliative care. The examples indicate that both carer and healthcare professionals had tacit rules of conduct, and where these could not be reconciled, the only resolution was for avoidance with the medicine. It

highlights that non-compliance or resistance does not come without cost to those who are marginalised (Skeggs, 1997; Tyler, 2015; Bordere, 2016).

Particularly in healthcare settings, the perceived distance between clinicians and patients (and their carers) can have a significant impact, based on the normative expectations:

The good patients are afforded sympathy that, while partially based on a desire not to see another human suffer, also rests on social familiarity. Judgement premised on feeling is, in turn, both subtle and powerful in reproducing inequality.
(Sointu, 2017, p. 74)

Not all participants in this sample had such an experience. Highlighting Sheila's account draws attention to a particular nexus of conflicting and co-existing social issues. The relative absence of difficulty could be viewed to be linked to the affluence of other resources, be that wealth, education, or social standing. For those participants whose (previous) occupations or neighbourhoods suggested comparative affluence presented accounts with little barriers or challenges in their access of appropriate healthcare. Even where asked explicitly the issues were felt to be minor (for example, a delayed visit by an out-of-hours nurse). When an expectation is met adequately it can be difficult to articulate in detail how this impacts a trajectory without something better or worse to compare it to. However, what the absence of description points to is that for those that do very demonstrably struggle there is a clear conflict.

7.4.3 Systematic Asymmetries

Instances of troubling or difficult healthcare interactions were also expressed by participants as being in the non-communicative moments. Where either the participant or the healthcare professional did not communicate something and the left a lingering concern, worry or, worse, a poor outcome.

Debbie and Mary both experienced language or communication that was evasive and vague at what were critical times when planning for the last stages of life for the person they cared for. The chasm in understanding was filled by assumptions of the carer. Yet, for Natalie the doctors took the

decision to withhold information from her despite the inevitable outcome of her mother's death, she was not told in advance that they anticipated the end was as soon as it turned out to be. This is despite national guidelines (Gold Standards Framework) that encourages collaborative and communicative interactions between multi-discipline practitioners and the patient and their families.

For others such as Irene and Pamela they were preoccupied with self-doubt over their capacity and ability to interact with the healthcare professionals. In Irene's case she was able to call upon her daughter (who was a nurse) to attend important consultations to act as an additional person to sense check what was being discussed. However, Pamela did not have this available and instead was left internalising much of her frustration and worry when care or conversations were challenging.

Complaints were rarely made. For Natalie, Sheila and Ian their difficulties led to an immediate reaction whereby conflict and discussion was had with the healthcare professional in the moment. For these participants there was not any knowledge demonstrated or desire to take their issue further. Despite this they all talked with powerful emotion when recalling these incidents, which would indicate that these issues were not fully reconciled for them in their bereavement.

Other participants, such as Debbie and Linda, were aware of their ability to make a formal complaint. Debbie had previously been a hospital secretary and was therefore aware of the processes by which a grievance could be raised. She considered raising a complaint and in order to do so she requested the full medical records of her mother. Yet, despite writing a letter of complaint to the hospital she never sent it because, she expressed similar sentiment to Linda, who stated "What's the point?" once the person you have been caring for has died.

The challenges for participants extended beyond just in healthcare settings. George described the difficulties he had in obtaining the household adaptations he was deemed to require in order to care for his wife with early onset dementia. After the death of her husband, Irene expressed concerns

with housing and council tax. For Ian in addition to tenancy concerns, his focus in the immediate time after the death of his uncle, was accessing the social fund for funerals as he, and his family, were unable to access the finance to pay for his funeral without state help.

When Pamela described how an administrative error in the apportioning and payment for the care of her father between her and family and the local authority had meant that she was charged historic debt of £3,000. This debt was going to be deducted from her fortnightly Job Seekers Allowance payments for a projected period of over 11 years. Her reaction was one of resignation, not simply because it was too difficult to challenge, because she did try with the help of her sister. The reason she backed down was due to a feeling of moral and emotional obligation to the legacy of her parents. As she described: "I just don't want Mam and Dad's name blackened". In this instance the local authority succeeded due to the emotionally charged association Pamela has made of the debt and her deceased parents.

There are no guarantees that if a challenge or act of resistance it maintained, that there will be a positive outcome for the participant. Rather than changing the conditions they find themselves in, or the normative expectations suggested that they follow, the effort and labour may not be rewarded in an alleviation of their suffering. It is suggested:

Moral beliefs may sometimes endorse inequalities and relations of deference and condescension, but they also embody notions of fairness and conceptions of the good which can prompt resistance to domination. (Sayer, 2005b, p.952)

When being reasonable or deferent maintains the status quo, it can be difficult to push back. As Rose and Lentzos (2017) note, resilience can be seen as a conservative approach that recreates normative behaviours rather than allowing space for different expressions. The insinuation might be that you are the aggressor and, therefore, are deserving of the injustice you face. In this sense it explains not only why participants such as Linda, Pamela and Debbie do not progress with their complaints. But furthermore, it shows how

Ian, Sheila and George might be framed as agitators for trying to challenge their interactions or circumstances. This means that even when they do air a frustration, upset or grievance, the balance of power is not in their hands, particularly when “emotions have the tendency to be recognised as properties of the person, rather than as the result of social practice” (Loveday, 2015).

In exemplifying the narrative incidences as described by participants it highlights that the consequences of institutional failure rarely fall on the institution itself. The patient, carer and concerned family are faced with situations where their recourse is minimal and where there is any it is often through a bureaucratic route. Therefore, the consequences are felt by the carer and their family. This can leave them with emotional (anger, upset) or financial (by conferring debt) turmoil and impositions. It is clear to see where miscommunication, mistakes and failures by the institutions charged with care or support, have had a profound effect on the participants of this study. Those who had a relatively smooth, or ‘good death’, there was an absence of difficulty and acute distress. The challenges and anguish experienced by *some* and not *all* point to inequality.

7.5 Deviance from Norms

The previous section interrogated the exploitation of power by institutions upon the individual. This often required the participant to recount their retrospective interactions largely from when they were providing care. In this section I shall look at how navigating a new and different chapter of their life as it was unfolding, and how their grief was mediated or justified against a set of powerful social norms.

7.5.1 Transition into Bereavement

Understandably the death of the person whom they had provided a great deal of care for was an emotional time. Being a carer, and then losing that primary role due to the death of that person, whilst also attempting to grieve for the loss of other family members and loved ones, was described as feeling almost impossible at times. Trying to orient oneself in the face of a significant loss was challenging both in the immediate period – when

planning and financing a funeral were required – and also weeks, months and years later when other factors could make their desire to grieve in a particular way challenging.

Attempting to arrange a funeral was often the first task that the bereaved carer faced and this brought its own set of challenges. For some the difficulties of planning and organising were often made complicated by familial discord. The accounts that described this time were often bound up in how appeasing family or working toward resolution was either attempted or deliberately avoided. It highlights how even at a point, which is often suggested should be, of remembrance and reflection, an intractable sticking point can be so dominant as to very much shroud the recollection of this period of time.

There was a clear desire for many participants to seek methods of memorialisation that were personally meaningful and significant. For Helen this meant spending time searching online for jewellery and urns that would allow her to keep her father near for her and her mother. For Mary it meant going against the suggestions of others to sprinkle her mother's ashes with her fathers. For Natalie it meant keeping her mother's ashes in her living room.

As noted in the review of the literature, the *Five Stage Model of Grief* (Kübler-Ross, 1969) did not intend to provide a step-by-step, instructional process for dealing with grief. However, it would appear that there is a widely held belief that grief, loss and absence are things which should be worked through, processed and accepted. It is this acceptance that will free the grief-stricken and enable them to move forward positively and gratefully with their lives.

The participants in this research did not always display having 'accepted' their loss, in the narrow understanding of the Kübler-Ross model. One explanation may be that, not enough time passed since the death. However, what emerged as being significant was the conditions which participants found themselves in. Not having circumstances that allowed for grief to occur mean that bereavement could be made more difficult.

Often there appeared to be a tension between giving appropriate space and time to grieve, and to the immediate needs of family life and multiple responsibilities. This could mean that work commitments, caring for other relatives/grandchildren, or dealing with the administrative tasks that are associated with a person's death (notifying appropriate companies, etc) diminished the ability to work through their bereavement.

7.5.2 The 'Need' for Justification

For many participants in this research their plummet into grief and bereavement was once that they felt ill-equipped to deal with. In some areas of research it is understood that the loss of a significant social bond can throw a great deal of one's previously understood role and routine into a state of flux, at best, and risk their claim for legitimacy.

Multiple theories and practical approaches to medicalise and treat grief were not referenced by participants in this research. Some were anxious that they 'were going round the twist'. When even the clinicians and academics are at odds over what constitutes 'normal grief' (Pearce, 2019), then it is unlikely that those experiencing immediate and acute loss will be any better placed to orient themselves comfortably within an emotionally turbulent time.

Mary, Linda and George all referenced funeral traditions or 'etiquette' as a justification of their subsequent actions. Mary, for example, seemed buoyed by the words of the funeral director in deciding to have the body of her mother at home as opposed to the funeral home, when he said "It was like in the old days, where they had them in the parlour". Often seeking a precedent was done to defy the expectations or wishes of other family members who felt differently. Doing so was not always easy, yet it clearly signals that where it is felt there are pre-existing practices it can help neutralise the conflict, or at least assuage the guilt, associated with going against the desires of others.

For Pamela the death of her 23 year-old son, after his drug-taking led to his taking his own life (as she described it), presented a difference in grief to those she had previously known, such as that of her father. She felt that her son Luke was 'still floating'. In describing this she said to me, 'you're gonna think I'm absolutely dumb'. In the moment, I assured her that was not the

case, but it was clear she felt the need to mediate the potential perception of her disclosure.

Pamela was not alone in this and it was evident there was 'justification work' that some participants felt they needed to do in their narrative accounts. Describing persons or experiences that could invite judgement presented the interview setting with sometimes challenging moments, such as when Mary would frequently state "It's not morbid" despite no suggestion from myself as the interviewer that it was the case. Thinking beyond the perception of the individuals who felt that justification was required, what does this infer about the positionality they reside within society? This shall be further explored in a following section.

It is evident, verbalised by participants or not, a prevailing cultural expectation weighed heavily on some. The often present feeling that there was 'something wrong' with them or that they 'were going round the twist' highlighted their awareness of what societal norms expected of them. In attempting to assuage the emotional pain of their grief they gravitated toward forms of grief and ways of bereavement that, whilst accepted in the academic and somewhat the therapeutic communities, was less acknowledged or accepted more widely in society.

The consequences of this disconnect were clear in the difficulties participants had to reconcile their personal preferences against societal expectations. The worry and nervousness about how one would be perceived was a reoccurring concern for those attempting to understand and make meaning from their personal loss. Whilst Lloyd (2018) rightly states "Grief isn't prescriptive; it doesn't have a timeline or a set pattern" (p. 27) it would appear from the descriptions here that there is at least a feeling of such expectations of the bereaved.

The academic thinking on grief has moved forward over the past 30 years, it is informed by a richer and wider evidence base of research from a variety of disciplines. Once the preserve of psychology, bereavement is now widely studied by anthropologists, sociologists and cultural theorists. As Mallon (2008) succinctly implores "we need to hold on to the idea that grief takes as

many forms as there are grieving people” (p. 4). However, this awareness of multiple theories of grief is not enough. It is clear that some of those interviewed for this research feel the prospect of attack or judgement of their behaviour. Their concern reflects what can be argued to be the prevailing culture, or what they see to be the prevailing culture.

7.5.3 Shame and stigma

With opposition and judgement coming not only from wider society, but from *within* families, how can it be said that social class is a determining and defining aspect of their experience as marginalised in their role of carer and bereaved? Why was the need to explain and justify, or to hide or conceal their choices so stressful and damaging for participants? I would argue that they were actively seeking to avoid being policed and the shame that their choices risked having conferred upon them.

With greater societal inequality comes a greater importance on relative positionality. Societal expectations and norms are often the same for all, however the resources to draw upon are not the same for all. Whether this be financial, social, educational resource there are marked differences. However, the consequence of normative societal expectations is that those who fall short are subject to “invidious or shaming comparisons” (Peacock, Bissell and Owen, 2014b).

In his book *Distinction* Bourdieu (1984) described how importance is attached to particular cultural pursuits and attributes. This can be seen most vividly in the categorisation of high-brow (e.g. ballet and art galleries) and low-brow (e.g. football matches and reality television) culture. The consequences of this demarcation of what is considered ‘tasteful’ and therefore valuable, had been paid little attention. It was Goffman (1963) that described the power of stigma in making and determining those with ‘spoiled identity’. A politicised and positioned person is one who is subject to and the aim of stigma.

Bodies are inscribed with value by the society in which they exist. For those deemed to be ‘lacking’ (e.g. education, status, wealth) or not demonstrating ‘appropriate’ behaviour in interactions. For example, Ian’s interaction with his GP demonstrated an overt questioning of his level of education as an attempt

to silence him, and when Sheila initially attempted to mediate her response toward hospice nurses when she was frustrated.

The work of Skeggs (1997) that helped to understand and foreground the relational and discursive concept of respectability is key. Being respectable is often important. This would help to understand why some participants, such as Mary, Joy and Pamela, would either attempt to actively defend aspects of their accounts, or were concerned about the consequence of their actions and behaviour in terms of how others might perceive them. There is a vast disconnect between what is understood by academics to be acceptable, and therefore respectable, ways to grieve, and what it would appear people are doing in order manage and assuage their grief themselves. Open discussion may not always be the answer, but as has been highlighted some might benefit from knowing they are not alone in their approach to bereavement.

Tyler and Slater (2018) challenge us to not take for granted overly simplistic offers of solution to tackling stigma, for instance raising awareness, myth busting or talking and “opening up”. These measures do not account for the unequal “distribution of distress” (Davies, 2017) or the active structural mechanisms that produce and promote stigma. It has been argued that simply ‘opening up’ and talking about traumatic grief and bereavement, without due consideration, can actually be harmful (Walter, 2017).

Particularly where public services have been either privately commissioned or experienced budgetary cuts in the context of austerity, for instance mental health provision or bereavement counselling, glossing over systematic deficits in support or provision means those without private resource to recover will be further disadvantaged by simplistic solutions.

The next and concluding section will further explore and argue how shame and stigma function within a neoliberal capitalist structure. This is highlighted through the examples throughout the research how the struggles that participants faced, both by virtue of their situation and their relative positionality, are problematised by capitalism.

7.6 Neoliberal Death and Bereavement

The differences in the accounts of participants and the issues which they faced have been explored throughout this chapter in terms of how they relate to the relative positionality of persons. From interactions with doctors that imply an expectation of middle class normativity, or the concerns of traversing what is acceptable in times of grief or bereavement, those whose lives were characterised by relative disadvantage reported their attempts to feel comfortable, at peace, or even acceptable, were not always straightforward. But who benefits from this?

Death and bereavement in the neoliberal era may present the capitalist mode of production with a challenge. Rose (1999) notes that in neoliberal societies individuals are both “obliged to be free”, but within the constraints and expectations of the normative culture, despite the obstacles faced. Those who are grieving are less productive. The limits on the worth and value of those who are providing informal care, or experiencing grief and bereavement are held in contempt and painted to be undesirable or outright pathological. Despite this challenge there are arenas for it to develop new markets (for example with memorialisation urns, jewellery, mementoes). With some participants spending time and money to memorialise their deceased loved one with tattoos, jewellery and urns. However, what is culturally new can cause controversy or require explanation. For instance, Helen noted that whilst she was happy with her necklace in which she kept some of her father’s ashes she did not feel comfortable disclosing that was its purpose to everyone.

7.6.1 Tracing the Insidious Line of Classed Based Differences

In terms of defending or policing the actions of participants, it was notable that participants described at times having to explain themselves to family, friends, support workers, and healthcare professionals. This was by those who were both similar and dissimilar. To understand why the differences in experience displayed by participants in this research are important and illustrative of class-based relations, it is important to note the contemporary importance of the concept of social class that help frame this.

Social class has been long debated as to how it is defined, who it pertains to, and what are the consequences of it. For some time there was somewhat of a lull in sociological use of the term. However, as society continued to be divided it was clear that the topic required reassessing. W. Atkinson (2015) implores us to think it of being neither exclusively about life chance, nor about exploitation.

The denial of social class as a stratifying mechanism was not without consequence. The effect of simultaneously denying class as a structural division of society, whilst highlighting that inequality leads to difference, is that those who are disadvantaged are described and charged with the blame for their situation and struggle (Tyler, 2015).

There are many examples within the accounts of participants, and as a consequence of being privileged to access the narratives, it is incumbent to make explicit the struggle for power. This power is not to be exerted on or over others, but simply the power to live their lives free of the judgement, and judgements' consequences, in a manner that is meaningful and satisfying to them at a time of loss and despair. Power resides in institutions, authoritarian professionals, and normative expectations. Ensuring that the status quo is maintained and individuals adhere to these principles.

Inequality remains a matter of class, even when it is not explicitly understood as such by those who perceive or indeed experience inequality. (Tyler, 2015, p.498)

There are clear instances where power imbalances based on a set norm inflict their might on individuals. Whether that individual challenges or acquiesces the consequences are frequently the same. Ian attempted to resist the inferences of the GP that he was not similarly educated, however without qualifications, status, or authority he was subject to the jurisdiction of the GP, whom had policy and law on their side.

Yet Joy and Pamela felt palpably their "lack" when interacting with doctors. In their fear of bothering doctors, appearing stupid or not understanding a medical response they shrank their being and identity in order to give space to the dominant status quo. This could have meant that HCPs inferred, as

some previous literature suggests, a lack of interest or investment in the medical interaction. This would be to misunderstand the consequences for the individual. As Mary suggested, long after the death of her mother she felt guilty for not having questioned certain things.

Whether standing up against or shrinking in when faced with the power dynamics the result was often the same; society is not structured in the favour of working-class individual. The accounts presented here suggest that this feeling is reflective of a wider societal problem. In order to access support at the end-of-life or in subsequent bereavement there is a clear set of normative expectations of how to behave and who to acquiesce to. It is clear that is more than simply a “feeling” or their perception. When the statistical evidence suggests growing societal inequality, the professionalisation of medicine sees its jurisdiction over the individual supported by policy and law, and the stigmatization of social problems labels those afflicted as deviant, it is clear that the feelings and perceptions of participants in this research are reflective of their subjugation and oppression.

Whilst trying to understand the complexities presented in the accounts of some of the participants, there were also those who did not present with worries, concerns, or descriptions of conflict with family or healthcare professionals. The absence of justification in these accounts is evocative of their respectability.

It is rarely recognised as an issue by those who are positioned with it, who are normalized by it, and who do not have to prove it. (Skeggs, 1997, p.1)

This power imbalance has exposed the difficulties faced by some participants, yet not by all. Society posits and demands of its members that they are free: “the well-being of all [...] has increasingly come to be seen as a consequence of the responsible self-government of each” (Rose, 1999, p. 264). The absence of concern or struggle amongst participants’ accounts was particularly insightful, as to those, who undertake what is seen to be by wider society as responsible self-government, were not preoccupied with fear

or anger that they may, or are, labelled as deficient. Peacock, Bissell and Owen, (2014a) state it clearly:

Neoliberal discourses thus cohere around a valuing of the self-regulating, self-surveillant and autonomous self, where those who are not equal to this task face both strain and fears that others will judge them as insufficiently responsible.
(p. 175)

7.6.2 The Path of (Least) Resistance

Resistance does not necessarily lead to effective change as Skeggs (1997) highlights: “To challenge powerlessness does not mean that one automatically shifts into positions of power” (p.11). This should come as no surprise, however there can be an expectation that disaffection and discomfort will lead to conflict as an attempt of resolution. In the context of caring for a family member, or grieving, it seems a stretch that individuals would, or should, feel compelled to seek justice when already managing many other responsibilities. Particularly when there is no guarantee of justice at the end. It would seem that some participants were even aware of this when they had considered or started the process of making a formal complaint within the hospital settings, yet did not see it through because, as Linda suggested, “What’s the point?”.

In grief, the difficulty around for carers of having accessed appropriate healthcare has the potential to add to the difficulty of bereavement. For those with traumatic experiences, this can be further complicated. Whilst some are aware and able to raise issues or complaints, this does not apply to all. Even those who are aware they can complain may feel that the death of their loved one precludes them for doing so, or they simply may not wish to raise the issue for the sake of their own feelings. Doctors may not be aware that the issues can have long reaching repercussions due to the disenfranchisement of the individual. This was the case for Mary, Ian, and Sheila. Those with more means or feel a greater stake of status in society may feel mobilised to do so in a way that further perpetuates the silencing of the voices of the disenfranchised.

It has been suggested that Bourdieu's notion of symbolic violence, and wider conceptual work, does not account for attempts to resist or challenge the pathologising of their behaviour they face (Skeggs, 2011: Tyler, 2015). There is evidence in the work of Skeggs (2011) that those she studied tried to resist "middle-class spectral judgement". Tyler (2015) credits this work as allowing for new explorations of working-class solidarity "in which people activate alternate values with which to deflect and contest class stigma" (p. 501).

This resistance can be evidenced in the ways in which participants in this research made, what they felt were somewhat, alternative choices in the memorialisation of those whom had died, and the support networks from which they drew upon in their bereavement. Such as Mary having the body of her mother at home, or Pamela having a memorial tattoo on her forearm, despite the protestations of their family.

It is important to return to the work of Skeggs (2011) here and interrogate where these choices that were made by participants were beyond the logic of capitalism? Taking the examples of urn jewellery, there is a burgeoning market for these items, and Helen herself had bought several pieces for herself and other family members. Acquiring these pieces does not in and of itself demonstrate an act of defiance of middle-class normative expectations of taste. Options are not made with or for these individuals, but rather for conscious commercial and profit-making enterprise.

Seeking out spaces of collective understanding and experience were highlighted, by the few participants who had found such spaces, as being vital to combat feelings of isolation and to share knowledge and experience. These were often linked with charities which funded the use of a community space and refreshments as a site for meeting collectively. Those who accessed it found it of great comfort, such as Helen and Joy. But as Debbie described, it is not always clear how to find or access these groups.

Furthermore, the charitable sector too is subject to a neoliberal market which in the past decade of austerity has seen the distribution of funding squeezed. Those who would usually access charities have themselves been victim and so charities see the need grow, not decline, as people require additional

support. This dependence is itself attacked and stigmatised. As Peacock, Bissell and Owen (2014) suggest: “Neoliberalism has ideological as well as structural dimensions, with ideology providing a rationale and legitimation for the social and economic priorities of the overall project” (p. 393).

The work of Peacock, Bissell and Owen (2014) that appeals to ‘collective imaginaries’ is exemplified by this research. These are tools and rhetoric that give cultural meaning, validation, and thus, strength to those usually derided. The atomisation and internalisation of shame and/or obedience that was expressed and alluded to by participants could have been resisted somewhat had their concerns and worries been ameliorated by examples and histories of others doing and feeling similarly. Yet their awareness was limited and this segregation of experience was exemplified when Mary asked, “It’s not sick is it? Is it? Are there any people [other than myself who do this]?”.

7.7 Conclusion

This chapter has explored the manner in which the findings of this research demonstrated a previously under researched topic and as such have established new and original insights. In doing so, this chapter has drawn on a wide body of sociological research and insight, beyond that of study area of death, dying and bereavement, to explain the structural power asymmetries that lie behind the shame, stigma and inequity that participants described.

The accounts given highlighted a range of experiences. What emerged clearly were multiple complex difficulties for some, and the absence of similar difficulties for others. These ‘difficulties’ pertained to domestic violence, alcohol and substance misuse, addiction, criminality, childhood sexual abuse, inheritance disputes, mental health issues, physical health issues, kinship care of family, etc. Facing these whilst also navigating care responsibilities for a family member who is dying, or the grief of that loss, was described as being challenging. This was further compounded by interactions with HCPs in which participants were faced with either acquiescing to their authority or challenging it for little to no reward. Further still, traditional notions of ‘doing grief’ left some participants feeling as though they were abnormal, or pathologically unable to ‘accept’ their loss.

Chapter 8: Conclusion

8.1 Summarising the Impetus for Investigating Experiences of Death, Dying and Bereavement in Working-Class Communities

This research set out to problematise the assumption that death is ‘the great leveller’. In response to the concerns laid out by Howarth (2007b) that whilst there has been a significant amount of work to improve understanding within the sociology of death, dying and bereavement, there has been a dearth in research in how inequality, disadvantage and social class effect and impact this part of the life course.

Given this impetus, the following research questions were set:

- In what ways does social disadvantage affect the experience of people at end-of-life?
- Do differences in cultural practices and class-based resources prove significant and formative for those people in disadvantaged communities who are providing care for the dying?
- How does the carer from a background of disadvantage negotiate the differences in occupation, educational attainment and/or cultural status between themselves and the healthcare professionals with whom they interact in their role as carer?
- Are these variations in background seen as significant by those at end-of-life and their caregivers?

A review of the literature described the range of sociological inquiry to death, dying and bereavement. This work gave greater insight into the range of issues faced and how society constructs and grants access at end-of-life to aid, such as hospices (Lawton, 2000). In addition, the arguably outdated, yet still popular understanding, of the stage-based model of grief was contrasted with contemporary insights into grief as healthy when expressed through continuing bonds (Lloyd, 2018; Pearce, 2019). There is a significant body of evidence that highlights the continued and increasing inequality, particularly in a UK context, has an impact on illness (Wilkinson and Pickett, 2010),

mortality (Schrecker and Bambra, 2015), and funerals (Sun Life, 2020). So, it too should follow that the qualitatively lived experience would highlight potential contrasts.

Understanding that inequality has an ideological dimension, the literature review noted the arguments made by those who suggest that inequalities, and particularly health inequalities, cannot be extrapolated from their political and socially classed consequences (Coburn, 2004; Scambler, 2018b, 2018a). Social class is a highly debated concept and, whilst it should be treated with caution and pertaining to metaphors rather than measurable and categorising dimensions, there is a clear a need to think of and hear the experiences of those who are deemed in deficit. The resource of capital (economic, social, cultural and symbolic) that are available play into determining factors of access, treatment, and risk of shame and stigma (Peacock, Bissell and Owen, 2014a; Tyler and Slater, 2018). In a political environment that suggests that individuals are responsible for themselves, it can be difficult to avoid the shame and stigma attached with the failure of the body at end-of-life, or the difficulties of achieving well-being in times of bereavement.

Based on identifying the gaps in the literature, this research aimed to use a feminist inspired narrative interview method. Recruiting through the third sector, community-based organisations and local faith leaders (amongst others) allowed access to a population of people who might have otherwise been overlooked. The interviews deliberately sought to disrupt the traditional power imbalance of the research setting, by giving control of the time, location, and most importantly, the discussion of their experience, to the participants. This generated a great deal of detailed information, which I was fortunate enough to be able to process and analyse for emerging themes, before undertaking a subsequent re-interview to check for corroboration of details and put questions to participants (serial interviewing).

8.2 Contributing Insight to End-of-Life and Bereavement Research

This section shall reflect briefly on some of the main findings and implications of this work.

The messy and difficult realities enmeshing of this research was a finding that appeared prominently and profoundly very early in undertaking the fieldwork. Inspired by the call of Wright Mills (1959) to understand personal troubles as public issues, these challenges were given initial focus, as so much that followed was done so in the shadow of their multiple sites of conflict and distress. The personal problems that some participants presented are very much seen and characterised as public issues. These readily identifiable public issues, such as poor educational attainment, criminality, pathological grief or domestic violence, were known by the participants themselves to be labelled as problematic. However, it is not the case that these issues are problematic in and of themselves. Often, the rhetoric that surrounded each, meant that a particular moral interpretation or framing was imposed upon them.

For some, this meant they had time, resource and support to “cocoon” themselves whilst adjusting to their loss. However, for others the challenges of disadvantage meant they were immediately required to attend to deal with any number of issues; potential homelessness and tenancy issues, mental health issues, alcoholism and suicidal ideation, debt and benefit sanctions, sexual and domestic violence, drug addiction and criminality, social services, kinship care and caring for other young or elderly family. Some participants even talked about not feeling as though they had been able to attend to their grief. Whilst this conjures problematic notions of grief as a mechanistic process which is to be worked through, it is clear that with competing priorities that require the attention and attentive involvement of the individual they deplete their ability to comprehend the loss they have experienced.

As caregiver the participants gave retrospective accounts of their interactions with healthcare professionals, funeral directors, and agencies of the state, such as local authority councils. For some participants, their retelling of these

relations appeared unproblematic. But others described problems, frustrations and upsetting issues, that continued to have a significant impact on their recollections, and consequently their bereavement. For some they believed that they were not capable themselves or were “thick as pig shit” and therefore at a disadvantage when conversing with the healthcare professionals. Concerns regarding the inadequate treatment and care for those from backgrounds that might be stigmatised (e.g. substance misuser) were evident, particularly when the expectation is that care and treatment should be accessible to all, regardless of background. Often these failures or problems were never addressed, it either was not considered worth it, or not considered at all.

The death of their family member signalled a break with their identity as a caregiver and conferred upon them grief and bereavement. Regardless of how much this had been anticipated, it was an emotionally challenging time for all participants. Arranging funerals could prove difficult, particularly if the wishes and plans of the participant were not also held by wider family members. This could mean that participants felt the need to justify their actions by appealing to historic rituals (e.g. having the casket with body in it at home). The expense associated with funerals proved difficult for those without economic capital to fund it and reliance on state welfare payments or friends and family was referred to.

After the funeral there were sometimes decisions to be made regarding memorialisation. Several participants kept the ashes of their cremated family member, with it being displayed in the home, or decanted and kept in urn jewellery. There were concerns that maybe this should not, or could not, be shared with everyone, and some people participants might hold back their decisions from. There was evidence of these decisions being policed, as with Natalie, who was instructed by her mental health support workers to remove the container of ashes from the living room of her home, because “yer just look n’it’s death”. Continuing a bond with their deceased family member did not appear to be as straightforward as the academic literature suggests (Klass, Silverman and Nickman, 1996). Multiple participants highlighted their

concerns that family, friends, or wider society might consider their beliefs and actions as “weird” or evidence that there was “sommat wrong with them”.

The differences that were displayed by this range of varied participant narrative accounts are best interpreted as highlighting continuing power struggles that some sections of society are subject to. These differences are indicative of wider hierarchical class-based inequalities. There were examples of difficulties with communications with authority figures such as doctors, police, or social workers where the participant felt unable to question or complain in the moment, or subsequently. There were also examples of family and friends challenging the caring responsibilities, or the funeral practices or memorialisation. Again, some participants resisted these social norms and structures that were forced upon them (bereavement is policed) by deliberately deviating from the norms, often at great costs to themselves and their families. For some participants, they felt they were at the sharp end of judgement and scrutiny by institutions and systems that purported to provide them with support. However, the symbolic violence that these interactions with professionals and institutions imbued upon them, often left them unable to question or resist, and attribute failings themselves.

Moments of resistance, as previously discussed, have been highlighted as being not fully conceptualised by Bourdieu’s work regarding social reproduction and symbolic violence (Skeggs, 1997; Tyler, 2015). This work would similarly evidence this shortcoming, noting that some participants attempted to reflect upon their actions and choices – whether it was in contesting the assumptions of doctors, or trying to memorialise in a personally meaningful way – and deflect against the shame and stigma they were explicitly or implicitly subject to. This required considerable emotional labour (Hochschild, 1983) and effort to provide interpretations of the symbolic violence they have internalised, and deflect this as really highlighting narrow or “channelled” normative behavioural expectations.

Particularly with regards to the doctor-patient relationship, and multiple modes of bereavement (such as continuing bonds theory), it would appear that there is a disconnect. Contemporary efforts in academia has researched

and provided evidence of injustice – such as, treatment of poorer and sicker people by doctors (Van Ryn and Burke, 2000) – and busting myths and assumptions – such as, highlighting the healthy manner in which bereaved persons can develop continuing bonds (Neimeyer, Klass and Dennis, 2014; Pearce, 2019). However, these discoveries are not ‘trickling’ or filtering down to those, who are evidenced in this research, can then we subject to harmful reactions and have stigma conferred upon them, due to their choices and preferences. Whilst power asymmetries, or the pervasive power of cultural and societal expectations, were evident and somewhat helpfully explained by Bourdieu’s notions of capital and symbolic violence, in attempting to understand the impetus and imperative for such entrenched modes of domination, contemporary sociologists provided deeper insight. It did not have the ability to account for all of the perceived and felt distress and worry that were described.

As I have briefly suggested, resistance of social and cultural expectations in periods of dying and bereavement, proved troublesome. Importantly, these attempts to resist, did not lead to meaningful change. Ian’s attempt to challenge the doctors over his perceived lack of educational credentials; Sheila’s demands for her son to leave the hospice after a conflict with nurses; Mary’s choice to have the body of her mother in her home prior to the funeral; Pamela’s seemingly controversial decision to have a memorial tattoo on her forearm. Yet the acts of challenging and resisting did not change the outcome of their situation (Skeggs, 1997: Tyler, 2015). They were not viewed with more legitimacy by doctors, nor were they supported by family members to be comfortable with their choices. All of these examples were recounted by participants in detail. For some there was evidence of long-lasting difficulty reconciling it, or desire to have been viewed or treated differently. But their pushing back did not change their lived circumstances or their perceived social placement in the hierarchy.

Peacock, Bissell and Owen (2014) demonstrate how these inequalities faced by participants can be seen as symptomatic of the trials of those attempting to find solace and compassion in a neoliberal society that emphasises individual responsibility and frames dependency as shameful. Their work also

helped to provide a glimmer of hope. The potential for resisting shame and stigma, by appealing to and accessing, collective imaginaries is encouraging. It was clear that participants were able to or trying to access spaces and rhetoric of commonality and reassurance, particularly when accessing carer support groups, or attending spiritualist events. Strengthening the acceptability and viability of these instances and places, could potentially help participants access mechanisms and discourses that emboldens their choices, not only to deflect and resist shame and stigma, but to become actively proud and fulfilled to be part of a wider community of shared experience and solidarity.

8.3 Personal Opinion and Reflexivity of Doing ‘Taboo’

Research

The narratives and stories represented in this thesis were not only important for voicing a forgotten/ symbolically violated group in end-of-life and bereavement research but were also very significant for me , as evidenced by the very visceral emotional responses that I had whilst undertaking this research. Despite attempting to steel myself for the sad and upsetting accounts that I would hear from those I interviewed, as was advised by my supervisory team, I was not prepared for the *anger, guilt and shame* that I would feel. I felt very comfortable with most of my participants, in a manner that I had not felt throughout my experience as a PhD student in academic settings.

The *anger* that I felt hit me like a tonne of bricks. The upset, bewilderment and rage that I witnessed in the reflection of their experiences was palpable. However, sometimes there was also resignation and disillusionment, which could be more challenging to reconcile. On more than one occasion, when driving back from an interview, I had to stop my car to record my tears of frustration at the injustice witnessed in my interviews, whose damage had already been done. Reflecting on, and attempting to pinpoint, where that anger came from was troubling and not one that I found easy to unpick within a middle-class academic context that mistakes emotion as weakness, pathological abnormality or just simply as uninformative. After much time

considering this, it is clear that anger is a rational and reasonable response to social injustice.

It may seem naive given that the fieldwork was designed to explore experiences of caring for a deceased family member, but I felt haunted by *guilt* for provoking further distress. Applying rationale and logic to justify to myself that the research is essential and needed, helped to a certain extent. Yet one memory recounted to me, which has not featured in the thesis as it has been too distressing to intellectualise, will always stay with me, gave me pause for thought and required the same mental effort to justify against.

End-of-life can be portrayed in a one-dimensional and linear manner, and by incorporating the experiences of diverse groups, we enrich this understanding. It is important work, but not easy work.

Leaving the field was challenging. In a reciprocal manner, the depth shared with me was often shared with them, and I felt very attached to some of my participants.

I felt tired, hollow and guilty leaving her. But I gave her a hand squeeze and was able to reiterate that I would come and see her again. But I still feel guilty now. (Excerpt from Fieldwork Diary after the first interview)

The *shame* of knowing that these relationships were generated with a particular aim in mind and that, as a 'good researcher', I should remain objective and distant, was and is constant. It is with regret that I stepped away from my fieldwork, and shame that I move on to pastures and challenges new.

It took me a very long time throughout my PhD to critique, not only the structural and societal context that my participants' experiences were situated in, but also the pervading narratives that attempted to shape what my own response 'should' be as a research scientist. Attempts to discuss these responses were not always met with understanding, and at the risk of drawing further questioning and scrutiny of the place of someone 'like me' in academia, I carried these emotions mostly alone. However, in becoming a

sociologist, my critical gaze has widened to include the academy. Social science has been dogged by a criticism that it is not scientific enough. But not all phenomena can be or should be quantified, made objective, or viewed as apolitical. Emotion is an important indicator. Reciprocal relationships should not be avoided. And all of this is deeply political. It may take time to overcome the perceptions of others that I am 'lucky to be here' or that as a working-class woman, I am capable of insight. Yet what has hindered my participants, I have in similar ways experienced myself, and their strength and courage gives me the inspiration to push on.

All of these challenges take time and effort to critique and argue against. These are issues that are being discussed more, but may not be shared by those closest in our intellectual efforts. Making connections, particularly in difficult times, is hard. Some of the personal troubles/social issues faced by my participants are ones that I had to contend with during the course of my PhD. Passing the test of traditional academia, whilst juggling the social issues in your personal life is draining. But the examples of my participants' determination have made me proud to have a connection with them and fuelled my desire to continue to provoke difficult debates in the area.

What is not discussed here, but is notable in its absence, and felt in my own life is the pressure to work. Care responsibilities of all kinds (but particularly those to older persons) are viewed as a burden, and as such we should treat the problem with the neoliberal market solution; pay someone else to deal with and resolve it. I learned powerfully from my participants that whilst care is often gendered and deemed a nuisance by a capitalist system that wants us to be nothing but productive and wage-earning, there were no regrets. No regrets, over the deeply intimate and personal moments and relationships they had with their since deceased family member. And so, all the pressure will not convince me that status or prestige as an academic is worth moving away from my mother or actively neglecting my care towards her.

Whilst this might seem deeply personal, and self-interested to divulge my struggle, the real aim of drawing attention to the very emotional response that I had throughout, and continue to have, is to underscore very strongly that

injustice is structural and has real consequences. The privilege of being a trained researcher is that we are given license to investigate it. Our burden is to push to make change a reality. For all of the emotions I have carried and will always carry as a result of doing research of this nature, it is an honour to have brought it to light and continue to showcase their experiences to provoke change in research, academia, policy and society.

For the authentic laughs and tear-soaked tissues, I shared with those who gave so much time, tea and insight to share their battles and lost loves; I can never be more thankful for. It is their experiences that have solidified my vocation as an activist against injustice, be that inside or outside of the academy.

8.4 Limitations and Their Lessons

As this research was a bursary PhD studentship, it had to have a fixed scope, due to limited resource, funding and time. In light of this, the research design, as previously described, had to be flexible and adaptable, and whilst that strengthened the recruitment, there were inevitable consequences (as outlined in the methodology chapter, which changed the focus of the research and the ways participants were recruited). The research intended to be an in-depth exploration of narrative accounts; however, it could be viewed as a small sample of 13. Some might suggest that this limits the ability of the research to make claims that could apply to the wider community and society. However, the rich material constructed with participants in the interviews, provide in-depth and novel insights of end-of-life experiences and bereavement of carers, and perhaps more importantly, frames these experiences as ongoing power struggles that enhance inequality through an enforced social class structure, which applies to other parts of society.

Whilst this research is grounded in feminist methodology and social justice aims, there was an evident gender imbalance in the sample. With women ($n=9$) being over-represented than men ($n=4$). It is widely documented that the nature of care, and of bereavement, is gendered. The focus of discussion and analysis would appear to overlook or omit an analysis of gender. However, there is rich data gathered that would have been of interest had

another perspective been applied. The impetus of this research was to investigate social class. However, it is clear that there is more to be understood, in particular with regards to the intersectional nature of gender and class at end-of-life and grief. Whilst there is research in this area, a closer investigation of the intersection of class and gender would be of great value.

Research presented here would suggest that there are distinct differences in gendered relations for death, dying and bereavement. For instance, whilst men were interviewed for this research, they were more likely to share the care responsibility with a female relative when compared to the women interviewed. The implications for women in their attempts to undertake care roles, be the centre of the domestic homestead and manage the emotional labour of not only those they care for but themselves in very testing circumstances, requires further investigation. The omission should not be viewed as a 'muted' critique of feminism (Lovell, 2004), as it has inspired this research hugely and given practical guidance on how to design and conduct research in a way that disrupts the traditional researcher-researched power dynamic, and unapologetically give participants a voice whom might otherwise have been left silent.

The sample does not include or represent any Black, Asian or Minority Ethnic (BAME) persons. Whilst there was nothing that explicitly precluded the involvement of any groups, the research setting of Teesside, as previously described, has been less ethnically diverse than the UK average. In learning throughout the research process (and working on many other projects) it has become clear that, those that are characterised as "hard to reach" populations, are often those that are "easy to ignore" by researchers and funders with tight resources, traditional research methods and narrow focus. Research presented here does not wish to fall under the criticism of being only about the "white working-class", in the manner of particular rhetoric that seeks to cause division, as we should see social class as intersectional. The disadvantage of this research is that it was unable to include narrative experiences of the diverse population of Teesside. Similarly, as to the call to

understand gender, further research that seeks to understand the intersection of class and race would be of great benefit.

Given the sensitive nature of the subject, it was necessary to not restrict recruitment in a manner that would potentially limit inclusion in the research. Therefore despite much consideration, the recruitment material did not stipulate that people of a particular social class were required or eligible. It would have been problematic to have specified a particular level of income, level of education, or employment status given the spurious nature of definitions of these things in relations to disadvantage, inequality or social class. Similarly, there is a great deal of evidence which shows, that asking people to self-identify their social class status, can lead to significantly variable results. However, the difficulty and reluctance to operationalise the concept of social class prior to undertaking fieldwork meant that factors that indicated their positionality had to be deduced from their living circumstances, personal histories and the narrative accounts they shared. While some may argue that this is a more holistic approach to understand the individual, it too can be suggested that this makes it difficult to extrapolate these experiences to be indicative of broader social class differences, inequality and structural or symbolic violence.

As has been highlighted throughout the thesis, social class is a disputed sociological concept. The argument here is to not dismiss inequality as merely 'social difference', but rather as a systemic and structural gradient of multiple disadvantages and stigma for many. Yet, it is the case that the terms 'working-class' and 'middle-class' end up becoming shorthand:

This returns us to ambivalent meaning of the concept of class, as description of a given place in a social hierarchy and as a name for political struggles against the effects of classification. (Tyler, 2015, p. 507)

However, it is hoped that this thesis has made clear that the use of these terms has been an attempt to wrangle back the political and social justice agenda into an aspect of the life-course that all too often has overlooked these structural confrontations and adversities.

Those who took part in the research represented a self-selecting sample. Whilst I would not, and do not, condone the pressuring or coercion of potential participants to engage with research, it must be noted that in those coming forward to take part, there will also, invariably, be those who decided not to. As a result of this, the accounts presented may be judged, by some, to be partial and that those in-depth accounts cannot represent or speak for an entire community. There may be some note to caution. However, these accounts do not attempt to speak for all. What they do represent are rich, profound and complex narratives of experience that might otherwise not have been gathered at all, had it not been for the readiness of myself to adapt and alter the approach to recruitment into the research.

8.5 Recommendations: Practice, Carers and Academic

Throughout the research, it was clear that there were issues that could have a detrimental impact on organisations that attempted to provide support, and more keenly, the lives of participants themselves, and their wider communities.

8.5.1 Practice

Healthcare settings and healthcare professionals should aim to reflect upon their own internalised prejudice and be prepared to challenge their working practice in order to mitigate the worst effects of their negative assumptions of those from disadvantaged backgrounds and working-class communities. This would require a more nuanced approach than that of the 'factfile' solution, highlighted by Gunaratnam (1997) in hospice settings. One that worked with families and communities to identify meaningful ways to accommodate differing needs, and addressing and dismantling stigma of particular persons and groups.

The accounts of the participants evidenced what appeared to be a reluctance of healthcare professionals to address and communicate clearly the proximity to death, what to expect regarding symptom management, or which healthcare professionals would be responsible for care. Whilst evidence elsewhere notes that healthcare professionals value the Gold Standards Framework in aiding multi-disciplinary communication and planning between

professional caregivers involved (Walshe *et al.*, 2008; Kinley *et al.*, 2014), it has not necessarily translated into improved outcomes for patients.

Meaningful and regular consultation of bereaved carers and families might help to identify areas for improvement in the GSF to ensure that similar upsetting and difficult situations are avoided going forward. Identifying good practice, as is perceived by those who are personally impacted by good or poor care, is key to ensure that guiding protocol and practice to not inflict harm on those at the end-of-life or the families who will carry any failures in their memory and into their subsequent bereavement.

There appeared to be a lack of clear signposting for carers, the ill and their families with regards to what support was available. This was evident in numerous ways, such as:

- Unclear, and potentially evasive, conduct with regards to obtaining occupational therapist assessments and subsequent council support for adaptations and aids in the home
- Not being told what medication or pain management was available as part of a palliative care pathway
- There is a lack of information provided as to what financial support could be drawn upon, such as carers allowance, sickness or disability payments, or bereavement grace
- Little information or awareness was available to participants on how to make a complaint about care received in a healthcare setting and therefore many didn't bother despite experiencing upsetting issues
- Prior warning was not given to those who might have to be asked routine questions by the police due to the sudden nature of the death, which could be affronting and upsetting
- No clear information on how to contact or access appropriate charities in a timely manner was available to participants that could have provided information, insight or support.

These issues could be addressed with further training given to those who work with or provide care, support and treatment to patients and publics. Ensuring that professionals have a clear awareness of support measure that they themselves can offer, or other complementary services can offer, would

aid people facing challenging circumstances. Taking the financial consequences as a salient example, an intervention designed to provide welfare rights information in healthcare settings to cancer patients showed clear, demonstrable beneficial consequences for those who received it (Moffatt, Noble and White, 2012).

A clear example of the need for this benefit was evidenced in the story of Natalie, who would have had an increased need for support from charities, as she was not only caring for her mother who had breast cancer, but she was also diagnosed and subsequently treated for the presence of cancer herself. Several participants noted that there could be an expectation that they themselves were the ones who had to seek out the support of charities, all the while being expected to continue and manage the demands of their situations. The lack of signposting or referral was surprising to the carers in hindsight, given the size and seeming ubiquity of health-related charities. More time and space within interactions or consultations to assess and aid the individual and their family would be a significant improvement.

8.5.2 Carers and their families

Addressing issues, such as those arising from the ideological function of shame and stigma are challenging. However, it need not be that hands are thrown up in despair. As previously discussed, I personally found it very difficult to manage the negative emotions when faced with the oppression and injustice faced by some of the participants. Yet, their strength was inspiring, as was the capacity for curiosity in times of isolating tragedy. Participants would ask (example of Mary doing so in Chapter 6) if other people I had spoken to faced similar issues. Whereas, Helen actively sought out ways to make her grief meaningful and shares it with others.

This capacity for curiosity and seeking shared experience, whilst small examples, was further emboldened by the work of Peacock, Bissell and Owen (2014), in their description of collective imaginaries. These imaginaries could act as a potential mechanism against, or reprieve from the symbolic violence suffered as a result of falling foul of a dominant societal or normative cultural expectation. Trade unions are an example of a way in which the drive

towards individualism has been resisted, and pride has been held onto through collective solidarity. In terms of death, dying and bereavement, it may be speculative, but based on some of the insights of this research, some of the examples of collective spaces of solidarity have been carer support groups and spiritualist events. These provide a community of similarly effected people who often share characteristics and can become sites of shared knowledge, support and pride.

8.5.3 Academy

With regards to activism in the academy, for many, it seems uncomfortable or 'not proper'. This would, to some extent, be explained by the dominance of a scientific community that fetishizes objectivity as the only reasonable route to knowledge and understanding. However, where it is clear that injustice exists, it is an entirely reasonable, rational and admirable response to feel aggrieved by that (Scambler, 2019). If we as academics do not listen to, give a platform to and advocate as a consequence of these accounts, we run the risk of contributing to the subjugation of multiple modes of grief. To assume that, because bereavement theory has interrogated and theorised in a more diverse way, and that these insights have penetrated beyond the realms of academic chatter and therefore provided sufficient solutions in itself can lead to offensive suggestions. One example is a suggestion posited to me in receiving questions at an academic conference: "But grief is postmodern now. Or has postmodernism not reached Teesside yet? [Sniggers]" Sneering and snobbery are precisely what should be avoided in the study of grief and bereavement. Such comments, however tongue-in-cheek or flippant, perpetrate violence on the difficulties and suffering of those coming to terms with their loss and grief in circumstances, that may leave them more open to scrutiny and critique, with little to no ability to countenance such judgemental gaze. As academics, we should use our relative privilege to resist any attempts to shame or stigmatise these communities wherever possible.

8.6 Further Research and Implications

The research presented in this thesis suggests that those from disadvantaged and working-class background face a multiplicity of barriers and challenges whilst trying to navigate, the fundamental human experience

of dying, death and bereavement. In doing so, it has given insight where previously there was little understanding. This is by no means definitive or exhaustive and there remains much to be understood. Here I shall discuss some pertinent lines of exploration and enquiry to strengthen the findings and arguments presented in this thesis.

As an act of action sociology (Scambler, 2019) the argument has been explicit in refuting the explanations of inequality that at best, simply fail to make the connection to class-based structural injustice, and at worst, are complicit in the obfuscation by employing terms that distance, such as 'disparities', 'difference' or 'variations', from the neoliberal capitalist agenda to seek profit before addressing human need (Coburn, 2004; Peacock, Bissell and Owen, 2014b; Scambler, 2019). However, there is much work to be done in order to further evidence the economic, social and cultural barriers that are faced by those who are providing care for a family member at end-of-life, and their subsequent grief and bereavement, particularly in relation to their social-class position. We need to ensure that the challenges faced by people in moments of crisis are not overlooked or dismissed as 'personal troubles' (Wright Mills, 1959), we need to make the case by couching them in, and explaining their integral relevance and intractability with symbolic and structural issues of oppression and violence.

Participants in this research were generous of their time and their biographies. In doing so, they provided insight into very personal stories and events. Their discussion of these was often described in highly individualised terms, and this is reasonable given their responsibilities as the primary carer, and then the very isolating grief they felt due to their loss. By actively listening and reflecting (Back, 2007), the interviews and their subsequent re-interviews allowed for greater understanding of their experiences, and allowed for sense-checking questions to establish where differences between accounts might lie.

I would advocate for this method of serial interviews, particularly with regards to sensitive topics such as end-of-life and bereavement. I believe the discipline has yet to utilise this method to its fullest potential, one which

prioritises the time and experience of an individual, but allows for further checking, and gives participants a level of control, by adding to, clarifying, or updating the researcher on their perspective. To assume their narrative accounts are a one-time or static event would be simplistic. Therefore, further research in this area could benefit from using a similar method to attempt to gain further understanding of the issues faced by working-class communities at the end-of-life and also grief. Additionally, it is suggested that further research in the area of dying, death and bereavement would benefit from a similar community-based recruitment approach to give voice to the differing 'illness journey' narratives that were uncovered here.

Death, dying and bereavement, are an emotionally challenging part of the life course. While this may appear common sense, this work has distinguished points at which the common sense, or expected, become troubled. By identifying instances of conflict, discomfort and distress, that were caused by other problems this research took seriously the challenges posed to participants in not only narrating their accounts without referring to them but, in doing so, clearly demonstrated that those facing multiple issues found it to impact on their ability to grieve. Reflecting on the absences in the accounts of some participants, it became clear that the instances of domestic violence, alcohol and substance misuse, criminality, mental health issues – to name but a few – were indicative of more than 'private troubles' and rather constituted 'social issues'. This claim is further evidenced by the shame and stigma faced by or perceived to be a threat to, participants in their attempts to provide care and/or adequately attend to their grief in a manner that fulfilled them.

The notion of social justice is a relatively new consideration in the academic research and literature around dying, death and bereavement and must not stop here (Bordere, 2016). This research could be strengthened by further investigation in this area by looking at intersectional issues. The white, working-class are by no means those only subject to lack of understanding, that then leads to judgement, stigma and shame. These act as barriers to services, treatments, and a sense of belonging in the broader community and society. I would hope that with a new interest in interrogating issues of equity

and social justice at the end-of-life and in bereavement, this research can act as a catalyst for change.

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Appendices

Appendix 1: Recruitment Poster



Teesside University is sponsoring this project for the purposes of research governance

Caring Today

Information for Potential Participants

Would you like to take part in a research project?

I want to look at how people have managed who have looked after family members (or spouses/partners) at end of life.

What is this research about?

When someone is seriously ill or dying, the focus of attention is obviously on them, and the experiences of people who are looking after them can often get less notice. I am interested in:

- What family members go through at such a difficult time
- Practical aspects such as how you interact with doctors, hospitals or other agencies
- How easy or hard it was to get support from family, friends or others in the community.



Who do I want to talk to?

If you were involved in the care of someone (a family member, spouse/partner, or friend) who has recently died within the past 3-12 months then I would like to hear about your experiences.

What will happen to me if I take part?

You will take part in a series of one-to-one interviews with the researcher, Stephanie Mulrine. If you take part your experiences and views will help inform how caregivers in Teesside can be supported. The interview might bring up sad thoughts for you. If at any time during the interview you find any of the questions raised upsetting or distressing please let me know and I can take a pause or stop altogether. You are free to withdraw your participation and any of the information you have given at any time for up to a month after each interview. All the information you give will be held confidentially and your name will never be used in any report.

Who can I contact for more information or to take part?

If you wish to request an **Potential Participant Information Pack** for more information to help you make your decision there are a number of ways you can get in contact with the researcher, **Stephanie Mulrine**.

Stephanie Mulrine, PhD Student,
School of Health and Social Care

Address: Teesside University,
Middlesbrough, TS1 3BA.

Telephone: 01642 384143

Email: s.mulrine@tees.ac.uk

Thank you very much for taking the time to read this information.

Appendix 2: Leaflet

Front page



Teesside University is sponsoring
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research governance

Caring Today

Information for Potential Partic-

Would you like to take part in a research project?

This study is looking at the experiences of people who have looked after family members (or spouses/partners) at end of life. Please read the following information carefully before you decide if you want to take part.

What is this research about?

When someone is seriously ill or dying, the focus of attention is obviously on them, and the experiences of people who are looking after them can often get less notice. We are interested in:

- What family members go through at such a difficult time
- Practical aspects such as how you interact with doctors, hospitals or other agencies
- How easy or hard it was to get support from family, friends or others in the community.



Who do we want to talk to?

If you were involved in the care of someone who has died within the past 3-12 months then we would like to hear about your experiences.

Middle pages:

What will happen with what I tell you?

All the information you give will be held confidentially and your name will never be used in any report. All information will be stored securely at Teesside University for 6 years. Electronic files will be held securely on a password protected university server. Paper files will be held in a locked filing cabinet. The only person who will have access to this data will be the researcher, Stephanie Muirine. When the research is finished a short report can be sent to you, if you wish.

Only if you were very upset or there was a potential safety issue for you or someone else would I tell someone you were participating in the research.

Can I change my mind about taking part?

You are free to withdraw your participation and any of the information you have given at any time for up to a month after each interview.

Do I have to take part?

No. It is entirely up to you.



What will happen to me if I take part?

If you wish to take part you need to send back the reply slip or phone Stephanie Muirine, at the number at the end of this leaflet. She will then contact you to arrange an appropriate time and place that suits you to conduct an interview. The interview will last no longer than 90 minutes. Before the interview takes place you will have the opportunity to ask any questions you might have and you will be asked to complete a consent form.

If you are happy with this, you might be invited to take part in other interviews at later intervals to see if things change for you over time. There will be no more than four interviews in total and you can pull out at any time.

Each interview will audio recorded. This is just to allow the researcher to capture what you have said and concentrate on the discussion without having to take notes. This recording will be kept confidentially and securely.

If at any time during the interview you find any of the questions upsetting or distressing you can take a pause or stop altogether. If you are very upset we can arrange for you to have some support from a qualified professional.

What are the possible advantages and disadvantages of taking part?

If you take part your experiences and views will help inform how caregivers in Teesside can be supported.

The interview might bring up sad thoughts for you.

Back page:

What comes next if I wish to take part?

There are a number of ways you can let the researcher, **Stephanie Mulrine**, know if you wish to take part.

- You can return the *Expression of Interest Slip* at the bottom of this leaflet and return it to the following address: Health and Social Care Institute, Teesside University, Middlesbrough, TS1 3BA.
- *Alternatively*, you can contact the researcher directly on the following details: Stephanie Mulrine

Telephone: 01642 384143

Email: s.mulrine@tees.ac.uk

Who can I contact for more information?

The research is being undertaken by Stephanie Mulrine who is a PhD student at Teesside University. For more information contact: Professor Janet Shucksmith, School of Health and Social Care, Teesside University, Middlesbrough, TS1 3BA.

Thank you very much for taking the time to read this information.

Your name: _____

Your address: _____

I am interested in taking part in this study. (Please tick box)

My contact details are:

Telephone: _____

Email: _____

The best time/day to contact me is: _____

Appendix 3: Interview Consent Form



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this project for the purposes of
research governance

Caring Today

Consent Form – Interviews – Family members/Carers

Name of researcher – Stephanie Mulrine

Please put your initials in the boxes to indicate your agreement with the corresponding statements.

1. I have read and understood the information sheet dated 10/02/2014, for the above study and have had the opportunity to ask questions.
2. I am aware that participation in the project is voluntary and I have the right to withdraw at any time up until one month after each interview. I understand that I do not have to give a reason for withdrawal and none of my rights will be affected.
3. I agree for my discussions with the researcher to be tape-recorded.
4. I have been assured that anonymity and confidentiality will be maintained at all times.
5. I understand that if I reveal any information that raises concerns about my or others risk of harm, the researcher may have to take this further.
6. I understand that my data will be held securely at Teesside University and will only be accessible by the researcher. Once the final report has been submitted the data will be archived for up to six years, after which it will be confidentially destroyed.
7. I agree to take part in this study.

Name

Date

Signature

Name of Researcher

Date

Signature

Appendix 4: Cover Letter



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research governance

Address: Health and Social Care Institute,
Teesside University,
Middlesbrough,
TS1 3BA.

Telephone: 01642 384143

Email: s.mulrine@tees.ac.uk

Date: 10/02/2014

Dear Family Member,

My name is Stephanie Mulrine and I am a PhD student at Teesside University. I am doing some research that looks at the experience of people who have looked after or cared for someone like a family member or partner at the end of their life. You are invited to take part in this research. This information pack contains an Information Sheet, an Expression of Interest Slip and an envelope (which does not need a stamp). To help you decide if you wish to take part, please read the information provided. You may speak to others if it will help you decide. Please feel free to contact me directly if you have any questions.

Yours faithfully,

Stephanie Mulrine

Appendix 5: Participant Information Sheet

Page 1:



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Information for Potential Participants

Would you like to take part in a research project? I want to look at how people have managed who have looked after family members (or spouses/partners) at end of life. Please read the following information carefully before you decide if you want to take part.

What is this research about?

When someone is seriously ill or dying, the focus of attention is obviously on them, and the experiences of people who are looking after them can often get less notice. I am interested in:

- What family members go through at such a difficult time
- Practical aspects such as how you interact with doctors, hospitals or other agencies
- How easy or hard it was to get support from family, friends or others in the community.



Why do I want to talk to you?

You have recently been in contact with services at either the George Hardwick Foundation or Tandem and they have agreed to give you this information and invitation on our behalf, because you were involved in the care of someone who has recently died within the past 3-12 months. The staff have not passed on your name or address.

Do I have to take part?

No. It is entirely up to you. Whatever you decide, you will still have the same support and access to services from the George Hardwick Foundation/Tandem. Your rights will in no way change.

What will happen to me if I take part?

If you wish to take part you need to send back the reply slip or phone me, Stephanie Mulrine, at the number at the end of this sheet. I will then contact you to arrange an appropriate time and place that suits you to conduct an interview. The interview will last no longer than 90 minutes. Before the interview takes place you will have the opportunity to ask any questions you might have and you will be asked to complete a consent form.

If you are happy with this, you will be invited to take part in other interviews at later intervals to see if things change for you over time. There will be no more than four interviews in total and you can pull out at any time.

Each interview will be audio recorded. This is just to allow me to capture what you have said and concentrate on the discussion without having to take notes. This recording will be kept confidentially and securely.

If at any time during the interview you find any of the questions raised upsetting or distressing please let me know and I can take a pause or stop altogether. If you are very upset I can arrange for you to have some support from a qualified professional.



What are the possible advantages and disadvantages of taking part?

If you take part your experiences and views will help inform how caregivers in Teesside can be supported.

The interview might bring up sad thoughts for you.

What will happen with what I tell you?

All the information you give will be held confidentially and your name will never be used in any report. All information will be stored securely at Teesside University for 6 years. Electronic files will be held securely on a password protected university server. Paper files will be held in a locked filing cabinet. The only person who will have access to this data will be the researcher, Stephanie Mulrine. When I have finished the research I will publish it and a short report can be sent to you, if you wish.

Only if you were very upset or there was a potential safety issue for you or someone else would I tell someone you were participating in the research.

Can I change my mind about taking part?

You are free to withdraw your participation and any of the information you have given at any time for up to a month after each interview.

What comes next if I wish to take part?

There are a number of ways you can let the researcher, **Stephanie Mulrine**, know if you wish to take part.

You can return the Expression of Interest Slip included in this Information Pack and return it in the pre-paid envelope provided (you don't need to put a stamp on).

You can give the Expression of Interest Slip to the staff member at the George Hardwick Foundation/Tandem and they will pass it on.

Alternatively, you can contact the researcher directly on the following details:

Stephanie Mulrine, PhD Student, School of Health and Social Care

Address: Teesside University, Middlesbrough, TS1 3BA.

Telephone: 01642 384143

Email: s.mulrine@tees.ac.uk

Who can I contact for more information?

The research is being undertaken by Stephanie Mulrine who is a PhD student at Teesside University and part of the Health and Social Care Institute. For more information please contact:

Professor Janet Shucksmith
School of Health and Social Care
Teesside University
Middlesbrough, TS1 3BA.

Telephone: 01642 342750

Email: j.shucksmith@tees.ac.uk

This research has been approved by the Teesside University Research Ethics Committee. If you wish to speak to someone who knows about but is not involved with the research please contact:

Dr Alasdair MacSween
School of Health and Social Care
Teesside University
Middlesbrough, TS1 3BA.

Telephone: 01642 342965

Email: a.macsween@tees.ac.uk



Thank you very much for taking the time to read this information.

Appendix 6: Expression of Interest Slip
Caring Today

Expression of Interest Slip

Your name:

Your address: _____

I am interested in taking part in this study. (*Please tick box*)

My contact details are:

Telephone:

Email:

The best time/day to contact me is: _____

If you are interested in taking part please use the self-addressed envelope to return this slip.

Or post to:

Stephanie Mulrine,
School of Health and Social Care,
Teesside University,
Middlesbrough,
TS1 3BA.

Or you can email: s.mulrine@tees.ac.uk

Or you can telephone: 01642 384143

Appendix 7: Topic Guide

Interview Schedule – Caring Today

Initial Story

Can you tell me what happened, as you remember, from her/his diagnosis up to now?

How are things for you now?

Family, Friends, Culture

Did you have support from the rest of your family? How did they cope?

Did you have support from neighbours or friends in the local community?

Are you able to turn for support now if you need it?

Healthcare

How were the doctors and nurses?

How did you/he/she find it talking to them?

Did you feel you could ask questions?

Did you feel he/she got the level of care he/she needed?

And do you think it was the same as other people might get?

Supporting Agencies

How were you referred to George Hardwick Foundation/Tandem?

Did you have contact with any other people/services/organisations other than the healthcare team or GHF/Tandem?

How easy or difficult was it to find information on these?

Impact

How did looking after [NAME] affect your job/money?

Did you get any benefits? If so, how did you know you were entitled and claim?

Was there anything in place to cover the cost of the funeral? Or did you have to seek support?

Demographics

Name

Age

Location

Occupation

Level of Education

Relationship to deceased

As above about deceased

Appendix 8: Photography Consent Form



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Caring Today

Photograph Consent Form – Interviews – Family members/Carers

Name of researcher – Stephanie Mulrine

Please put your initials in the boxes to indicate your agreement with the corresponding statements.

- | | | |
|-----|---|--------------------------|
| 8. | I am aware that participation in the project is voluntary and I have the right to withdraw at any time up until one month after each interview. I understand that I do not have to give a reason for withdrawal and none of my rights will be affected. | <input type="checkbox"/> |
| 9. | I agree for the item to be photographed by the researcher as discussed. | <input type="checkbox"/> |
| 10. | I have been assured that anonymity and confidentiality will be maintained at all times. | <input type="checkbox"/> |

Name

Date

Signature

Name of Researcher

Date

Signature

Appendix 9: Poem from Joy's Ungiven Birthday Card

The text from the card reads:

Front:

"For My Wife with love on your Birthday,

Your love has made all the years we've shared the best that they can be,

And, looking back, I would not change a thing - you mean everything to me."

Pg 1:

"There are so many moments that mean so much,

Moments we've shared through the years..."

Pg 2:

"I remember companionship, friendship and love, happiness, laughter and tears..."

Pg 3:

"I remember the times we've made dreams together,

And how proudly we've seen them comes true..."

Pg 4:

"I remember our busy times - side by side, hand in hand,

Our quieter, relaxing times, too..."

Pg 5:

"I remember the times that you've told me you loved me,

And the many ways you've showed that you cared..."

Pg 6:

"I think of the joys our marriage has brought,

And the happiness we've always shared..."

Pg 7:

"And I know, though these moments are precious to me.

For the things that were said and were done,

It's you and your love that make each one so special

And our life such a wonderful one!

I love you very much

Happy Birthday"