

# **Exploring the Social Construction of Grief and Loss in Spouses Following Bereavement by Cancer**

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## **ABSTRACT**

Cancer bereavement may be associated with unique challenges involved in the caregiving experience, particularly for spouses, who commonly adopt this role. However, the dominance of quantitative and diagnostically informed research has produced a-contextual theories, which reinforce increasingly medicalised conceptualisations of grief. In contrast, less attention has been given to the subjective experience in this context, particularly from a discursive perspective.

Three focus groups comprising an overall total of six men and 17 women were used to facilitate discussions between spouses who were bereaved by cancer. A Foucauldian-informed discourse analysis was employed to examine how participants constructed grief and loss, and to identify the broader discourses that served to shape these. Additional attention was paid to the rhetorical aspects of these constructions. Three overarching discursive 'sites' were identified: i) medicalisation; ii) individualism and iii) productivity and purpose.

Analysis of the discursive activity illuminated how these discourses co-existed, creating tensions within constructions that highlighted an increasing professionalisation of grief, and also carried expectations for individuals to manage their grieving in private, via practices of self-regulation. These discourses offered subjugated positions and served to reinforce the power differentials that exist between the bereaved and professionals. However, those constructions that resisted positions of powerlessness and being silenced enabled individuals a greater sense of authority within bereavement and led them to feel more open and connected as a result.

The findings draw attention to the expectation for bereaved individuals to protect society from their emotions. This has important implications for how grief may be better supported within clinical psychology settings and points to the need to challenge unhelpful assumptions within society.

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## **1. INTRODUCTION**

This chapter will begin by providing a critical overview of the dominant conceptualisations of grief and bereavement within the academic literature, including the epistemological assumptions that underpin them and the potentially problematic implications these may have for bereaved individuals. This will then serve as the basis upon which to compare alternative approaches to the study of grief, which will draw particularly on the wider discourses that surround the construct of bereavement. I will then outline my rationale for focusing specifically on cancer bereavement in spouses, drawing on previous research that has differentiated these groups and illustrate the significant absence of discursive approaches within the field. Finally, the key aims and rationale for the current research study will be presented, including the study's research questions.

### **1.1 Terminology and Literature Review**

The term 'bereavement' is widely understood to refer to the experience of losing a loved one who has died (Howarth, 2011), however it is also typically associated with a number of subtly distinct terms that feature across the field. In line with previous literature and existing definitions, these will be defined for the purpose of the current study as 'loss', which represents the physical absence that follows death, 'grief', which refers to the emotional response to loss and 'mourning', which is used to describe the expression of grief (Stroebe, 1993). These terms carry subtly distinct conceptualisations. However, as Jakoby (2012) notes, these terms tend to be referenced interchangeably within lay language. Therefore, in actual conversations participants may use them in range of ways that differentiates them from their formal use within the literature. The above terms were incorporated into the search criteria used during my review of the literature, as were the terms 'death' and 'dying', given their inextricable link to bereavement and loss.

Initially, my review began within publication databases PubMed, PsycINFO, PsycArticles and was extended to additional databases (Cinnall Plus, Academic Search Complete; SCOPUS and Science Direct). I was also informed by key references that I sourced from within relevant articles. Of particular influence early on in this process were the papers 'Academic Constructions of Bereavement' (Valentine, 2006), 'Grief as a Social Emotion' (Jakoby, 2012) and 'A Social Constructionist Account of Grief: Loss and the Narration of Meaning' (Neimeyer, Klass, & Dennis, 2014), which inspired and shaped the subsequent direction of my work. Specifically, I was interested in finding qualitative research that captured experience and meaning of bereavement from the perspective of the bereaved themselves and as relevant to my research questions. Further details of my extensive reviewing process, including a full list of the search terms that I employed can be found in Appendix A.

For the purpose of the current study, the term 'discursive site' is defined as the location in which several over-arching discourses may operate.

## **1.2 Dominant Perspectives of Bereavement**

Historically, the formal, empirical study of grief and bereavement traces back to the early 17<sup>th</sup> century (Parkes, 2001), resulting in an extensive array of theoretical approaches that have attempted to account for the experiences that follow the death of a loved one. Given the breadth of the topic, which spans over a century of research, an exhaustive review of the literature is beyond the scope of this chapter. Instead, the aim is to critically track key theoretical developments within the field, drawing on relevant research that has been particularly influential in shaping clinical practice and informing lay understanding in broader social contexts.

### 1.2.1 Freud's Grief Work Theory

Freud's *Mourning and Melancholia* (Freud, 1917) initiated the expansion of research into grief within mainstream psychology, providing a framework of assumptions about bereavement that remain influential almost a century later (Lister, Pushkar, Connolly, 2008). His grief work hypothesis outlined grief as the process of withdrawal from the emotional attachment to the deceased, enabling the development of new attachments and resulting in a return to 'normal' (Lister et al., 2008); the necessary endpoint of resolution (Lindemann, 1944). As a process, grief 'work' was considered to follow a predictable course over specific phases of time. Furthermore, the particular focus on individual internal states in isolation from their social context underlined grief as an inherently intra-psychic process.

### 1.2.2 Stage Models of Grief

The assumptions of resolution and a necessary endpoint to grief continued to infiltrate mainstream models of bereavement, featuring as a key tenet within the stage theories of grief. Progressing from her stages of loss model (following her work with patients who were terminally ill), Kubler-Ross (1969) argued that bereavement involved the transition through five stages of grief, comprising denial, anger, bargaining and depression. Building on this, Worden (1991) emphasised the importance of personal agency within bereavement, outlining a number of 'tasks' of mourning, which included acceptance of the reality of the loss and the need to 'work through' grief.

Despite theoretical developments within the grief literature, the stage approach has been powerfully influential in shaping the provision of bereavement services (Payne, Jarrett, Wiles et al., 2002) and has permeated lay understandings of grief within society (Valentine, 2006). It is important to note that these models frequently inform bereavement interventions, which focus on supporting individuals to progress through their grief and find a point of 'resolution' that enables them to 'move on' (Gauthier & Gagliese, 2012; Breen & Connor, 2007).



### 1.2.3 Medicalisation of Grief

Whilst grieving was previously understood as being a natural response to death, increasing shifts towards a biomedical framework within Western society (Kleinman, 2012) have led to the pathological reframing of grief as a psychiatric illness for which people need to be treated (Valentine, 2006). Engle (1961) influentially likened grief to a disease, in order to legitimise its scientific study and encourage its acknowledgement through medical diagnosis and treatment (Stroebe, 2015). The somewhat controversial inclusion of grief within respective versions of the Diagnostic and Statistical Manual of Mental Disorders (e.g. 5th ed.; DSM-5; American Psychiatric Association, 2013) is a further reflection of this shift. In addition to the ever-changing and arbitrary cut-off points that differentiate grief from a diagnosis of depression, this inclusion reinforces assumptions of a definitive and normative recovery period. As Kleinman (2012) points out, not only does the scientific evidence for this remain inconclusive, but also further, the assumptions relating to the trajectory of grief vary greatly across cultures.

More recently, additional classifications for atypical grief include 'complicated grief', and 'prolonged grief disorder', both of which are conceptualised as being clinically distinct from depression, anxiety, PTSD and 'normal grief' (Breen & O'Connor, 2007). These constructs were developed in response to clinical observations that a proportion of grieving individuals remained in high states of emotional distress and developed trauma 'symptoms' in response to loss, which interfere with grieving (Howarth, 2011). The terms are also characterised by the failure to adjust to the loss, and difficulties with interpersonal and occupational functioning (Guldin, Jensen, Zachariae, & Vedsted, 2013).

Valentine (2006) raises concern about the use of medicalised language such as 'abnormal', 'chronic' and 'prolonged' within bereavement, arguing that these perpetuate the notion that grief is a pathological response to death that requires medical treatment. In line with this, the management of grief has been

increasingly associated with the prescribing of psychotropic medication (Kleinman, 2012; Guldin et al., 2013).

Taken together, traditional conceptualisations of bereavement carry dominating assumptions in which normal grief is differentiated from pathological grief, in accordance with expectations of a time-limited 'resolution' and a prescriptive nature to its progression (Breen & O'Connor, 2007). Crucially, these approaches fail to encapsulate diversities within grief, including divergence across culture (see Valentine, 2009), the type of loss that was experienced or the bereaved individual's relationship to the deceased. Not only do these dominant assumptions influence wider societal understandings, which has implications not only for how people who are bereaved understand their experiences, but additionally impacts upon those around them including professionals working to support them. Breen and O'Connor (2007) warn that such "uncritical acceptance of the assumptions in the dominant discourse" (p. 202) has the potential to result in services that are unhelpful and social networks that are unsupportive, creating further distress should individuals' experiences of grief diverge from what is assumed to be 'normal' (Wortman & Silver, 2001).

### **1.3 Diverging Epistemologies: Implications for Research**

Contemporary bereavement research predominantly operates within a scientific framework. This is underpinned by assumptions of essentialism, in which objective 'truths' are seen as uncoverable, and human experience, as a consequence, is conceived of as measurable, categorisable and universal (Small, 2001). Implicitly, this framework prioritises the production of quantitative research (Valentine, 2006), which, together with the increasing biomedical influence within the field, has led to a wealth of bereavement research that seeks to classify features or 'symptoms' universal in identifying pathological from 'healthy' grief (Breen & O'Connor, 2007). Consequently, this perpetuates

mainstream constructions of grief as being a condition of the individual psyche (Small, 2001).

Critics argue that from this perspective, grief becomes dislocated from the social, historical and cultural contexts in which it is embedded (e.g. Jakoby, 2012) and the focus on intra-psychic processes fails to acknowledge the fundamentally interpersonal nature of loss (Valentine, 2006). Somewhat under-represented within the literature is the exploration of grief via the use of qualitative methodologies, which seek to examine the subjective experience of loss and grieving as constructed by the bereaved themselves. Rather than a pathological condition in need of treatment, or a universally prescriptive experience, sociological, narrative and discursive perspectives of bereavement examine the influence of the wider social and cultural context of death on bereavement. These perspectives consider grieving as fundamental to human life (Valentine, 2008). The next section will further examine some of the literature from within this perspective, so as to highlight the importance of meaning within grief, the interpersonal nature of bereavement, and the wider context within which this phenomenon takes place.

#### **1.4 Alternative Perspectives: Bereavement in Context**

Shifts towards anthropological and sociological perspectives have led researchers to take a more interactional approach to the study of bereavement, by placing greater emphasis on the negotiation that takes place between people, in order for bereaved individuals to make sense of their experiences (Valentine, 2008). This has revealed the highly diverse and complex nature in which people grieve, rendering existing assumptions of universalism both problematic, and inadequate in capturing people's experiences (Hockey, 1996; Neimeyer, 2004). As emphasised by Jakoby (2012), "death is a universal biological fact, but grief and its expression vary among individuals social groups and cultures" (p. 693). Two key and influential shifts within the understanding of bereavement come

from the model of 'continuing bonds' (Klass, Silverman & Nickman, 1996) and grief as a social construction (Neimeyer et al., 2014), which are outlined in more detail below.

#### 1.4.1 Continuing Bonds

The emergence of the 'continuing bonds' approach to grief (Klass, et al., 1996; Walter, 1996) within the literature takes account of the contextual nature of grief and directly challenges the dominant assumptions of 'severing ties'. In contrast, this approach developed following the observation that bereaved individuals frequently maintain relationships with their deceased loved ones (Klass et al., 1996), which appeared to provide them with solace and support (Klass, 1993).

The theory of continuing bonds has shaped a growing body of literature within the bereavement field and increasingly influenced bereavement counselling in practice (Mackinnon, Milman, Smith, & Henry, et al., 2013). Subsequent research within the area has highlighted that the deceased maintains a continuing presence and significance within the lives of many surviving individuals (Hallam, Hockey & Howarth, 1999), which may represent grief-specific coping strategies that enable individuals to connect to their loved one in order to reduce pain (Asai, Fujimori, Akizuki, et al., 2010). This suggests that while death can be considered as signifying the material loss of the deceased, this physical absence may not necessarily represent the loss of the shared relationship (Root & Exline, 2014). In line with this, a particular focus has been the influence that religious and spiritual beliefs have within meaning-making in bereavement (e.g. Davis, Nolen-Hoeksema & Larson, 1998), which can enable individuals to make sense of their loss and influence the future direction of their own lives (Golsworthy & Coyle, 2010).

In development of this, Gillies and Neimeyer's (2006) model of meaning reconstruction places significance on the impact that death and bereavement has on an individual's identity, and the deceased person's continuing influence within

this (Valentine, 2008). As a further emphasis of this, Bradbury (1999) asserts that when a loved one dies we lose the part of ourselves that was constructed via our interactions with them, giving explanation as to why grief can feel so painful. From these perspectives, grief is an inherently complex social and interpersonal process, shaped by relationships, attachments and through interactions between people (Jakoby, 2012).

#### 1.4.2 The Social Constructionist Approach to Grief

Social constructionism attends to the way in which phenomena are constructed through discursive activity such as language, and as informed by the availability of dominant discourses (Burr, 2003). In proposing a social constructionist account of grief, Neimeyer et al. (2014) emphasise the importance of examining processes of meaning-making as they are negotiated with other people through interaction and communication, following a loss. Dominant discourses also have important implications, as they are seen to shape grief experiences and mourning practices and powerfully influence society's response to the bereaved (Valentine, 2008).

Neimeyer et al. (2014) argue that rather than existing intra-psychically, the interpretation individuals make during grief and the meaning they draw from their experiences take place under the observation of family, friends and the wider community, as well as by those who hold religious and political power. This relates to Foucault's (1972) assertion that the availability of particular discourses (and the subsequent subjugation of alternatives) has implicit implications for power relations and its influence within society. Accordingly, the power and influence of dominant discourses become reproduced through what Walter (1999) has referred to as the 'policing' of bereavement by society. This has been referred to as 'feeling rules' (Hochschild, 1979), which govern the way in which individuals should think, feel and express their emotions. Neimeyer et al. (2014) suggest that the deviant expression of grief is managed and suppressed through the use of diagnostic categories of grief (as outlined in section 1.2), which serve

to identify and regulate grief in accordance with specific presentations and timeframes.

Whilst the employment of discursive perspectives would enable examination of the broader cultural and contextual influences surrounding grief and bereavement, the current review of the literature revealed a significant absence of research that takes such a macro-level approach. Nonetheless, the following sections will provide an outline of some of the influential discourses that feature in the available research. Of note is the valuable contribution made by Valentine (2008), whose narrative approach examined the ways in which bereaved people made sense of death and the social discourses that resourced their constructions.

#### 1.4.3 Discourses about Death and Bereavement

##### 1.4.3.1 *Medicalisation of death*

Valentine's research illuminated how narratives of bereavement drew on overarching discourses relating to the medicalisation of dying within contemporary society. Following the shift from religious to medical conceptualisations of death, dying became the responsibility of medical institutions, rather than an act of God (Richardson, 1987, in Valentine, 2008), placing authority within professionals' 'expertise' (Hockey, 2001). Medical discourses have been suggested as placing individuals in an inferior position in their relationships with 'expert' professionals (Glaser and Strauss, 1965). Furthermore, Hockey (2007) argues that the increased professionalisation of death may serve to undermine individual autonomy and impact on people's experiences of loss.

Valentine's study demonstrated the conflicting relationships that participants had with medicine and its professionals, as resourced by medicalisation discourses. This was constructed either as having trust in the medical authority (whom they

relied on to help them navigate the uncertainty of dying), or doubt, disappointment and resentment following failed attempts to prevent the death. The medicalisation of death necessarily conceptualises dying as a condition to be treated and as a consequence, death becomes the failure of medical treatment. The study's findings further illustrate how the increasing implementation of medical technology both served to maintain human dignity and created the perception of dehumanised dying, by prolonging an inevitable death. The value that is placed on humanised dying and the preservation of personhood within this is associated with discourses about the ideal of a 'good death'. These assumptions not only shape the way in which the dying are cared for, but further serve to influence experiences of grief (Bradbury, 1999). Valentine's study illustrates how the responsibility to endure this is often placed on the family of the dying individual. This was constructed by her participants as knowing they had done all they could for their loved one, feeling as though they were needed, and as feelings of doubt or guilt in their perceived failure in this.

#### 1.4.3.3 *'Death denial'*

Tracking the historical context surrounding death and grieving responses across the 20<sup>th</sup> century illustrates how the development of medical technology and increases in public health resulted in the vast reduction in the number of people experiencing death, in comparison to the first world war (Valentine, 2006). Mercer and Feeney (2009) suggest that the influence of an increasing biomedical framework in society has served to instil the fear of pain and death within individuals, perpetuating the avoidance that is enacted in its response. Such a death denial (Seale, 1998), or 'death anxiety' (Neimeyer Wittkowski, & Moser 2004) represents a dominating influence within contemporary Britain (Reynolds, 2002), which has important implications for the bereaved. In an analysis of an online survey relating to the communication that bereaved individuals engaged with about grief, Jakoby (2014) found that whilst the majority of respondents wanted to speak about their experiences, they often felt unable to share these with family and friends. The findings further highlighted that bereaved individuals

are infrequently asked about their grief, which is suggestive of the avoidance that is often associated with the subject of death (Seale, 2008). Furthermore, Jakoby draws attention to the fact that respondents felt particularly restricted in talking about grief beyond a certain period of time after the death, highlighting the influence of 'time to move on' discourses perpetuated by dominant theoretical perspectives.

#### *1.4.3.4 Capitalism and grief*

In her critical analysis of the construct of grief and the assumptions that underpin it, Harris (2009) examines the relationship between death and bereavement in Western society and the underlying social structures that are powerfully shaped by capitalist ideologies (Reynolds, 2002). Harris (2009) suggests that bereaved individuals represent a threat to the capitalist agenda, due to the high value that is placed on productivity and consumerism and the potential inability for grieving individuals to contribute to this. As a consequence, she argues that in order to avoid marginalisation, "individuals internalize the oppressive forces that are enforced through the social rules of acceptability after a loss occurs" (p.247). Whilst this perspective opens up the possibility to examine the broader level influences shaping grief within contemporary society, it represents a notable minority within the psychological literature.

The next two sections will address the specific impact of cancer and spousal bereavement. While the influence of the above discourses within these specific areas will undoubtedly be important (and may shape experiences of loss and grief in unique and nuanced ways), it is important to reiterate the significant absence of literature from this perspective, which examines the influence of the broader context within these experiences.



## **1.5 Cancer Bereavement**

As a consequence of increasing rates of cancer in the UK (Cancer Research UK, 2015), cancer bereavement has become a particularly prevalent and specific form of loss that requires negotiation of certain end-of-life experiences specific to terminal illness (Fasse, Sultan, Flahault, MacKinnon, et al., 2014). The growing research base within the area emphasises a number of important factors involved in the cancer trajectory that may impact on bereavement in important ways. These include the management of distressing symptoms associated with the disease and its treatments (Holland et al., 2010; Dumont, Dumont & Mongeau, 2008), interactions with healthcare professionals (Totman, Pistrang, Smith et al., 2015) and the experience of palliative care-giving, which can be emotionally draining (Payne, Smith, & Dean, 1999; Waldrop, 2007) and socially isolating (e.g. Holtslander & Duggin, 2010).

The following sections will give further attention to some of the specific factors considered pertinent in the experience of cancer bereavement by reviewing relevant literature adopting a qualitative approach, before going on to consider its specific impact on spouses.

### **1.5.1 Anticipation and Uncertainty in Cancer**

A further distressing challenge that many informal carers of terminal cancer must face is the witnessing of their loved one's physical deterioration (Waldrop, 2007). The impact of this has been frequently associated with the term 'anticipatory grief', which refers to the grief response that is often reported by individuals in the anticipation of the impending death of a loved one and extending into bereavement (Rando, 1983; Rando, 2000). Waldrop (2007) has proposed qualitatively distinct experiences of grief between that experienced during the end of life care and following the death.

Related to this, Olson (2014) highlights how with increasing medical advances, the expectation that death will necessarily follow a diagnosis of cancer is no longer a given, illustrating the impact of such uncertainty on people in the cancer caregiving role. Olson (2014) introduces the term 'indefinite loss' which characterises the sense of uncertainty facing individuals during the unknown trajectory of cancer, referring to a future loss that is possible, yet remains unknown. In comparison with anticipatory grief, indefinite loss relates to those future hopes, plans or sense of freedom, which are disrupted by the diagnosis.

These factors form part of the rationale for the need to incorporate bereavement support before and after the death of a loved one to terminal illnesses such as cancer (e.g. Johansson & Grimby, 2011; MacKinnon et al., 2013). From a post-structuralist perspective however, concepts such as anticipatory grief can be deconstructed to illustrate the broader contextual influences that underpin them. For example, Small and Hockey (2001) suggest that grieving in anticipation of death may serve to shape behaviour rather than to simply describe it. They assert that anticipatory grief acts as a rehearsal of the bereavement role, and serves as an indicator to professionals to intervene so as to facilitate 'appropriate' grieving in the absence of this behaviour. As such, this represents a socially-regulated practice.

### 1.5.2 Cancer Caregiving

Cancer has been described as being a "family illness" (Germino, Fife, & Funk, 1995, p.43), due to its impact on the relatives and close friends who take on the role of caregiving (Wong, Ussher & Perz, 2009). As highlighted above, palliative caregiving presents the family and friends of the patient who take this role on with particular challenges. Qualitative research to examine family members' lived experiences in providing current cancer-care highlight a range of factors that appear to have an important impact on this role, and which influence their subsequent experiences of grief.

#### 1.5.2.1 *Responsibility*

Totman, Pistrang, Smith, et al. (2015) point out that that relatives who adopt the caregiving role are typically required to take on high levels of responsibility, which impacts on their physical and mental health (e.g. Linderholm & Friedrichsen, 2010). In their study, participants described the burden of responsibility as a consequence of taking up this new role, such as feeling under pressure to 'get it right' and in ensuring they were doing enough for their relative.

Research carried out from the perspective of the bereaved highlights similar challenges that relate to the responsibility of being a caregiver and the impact this has on subsequent bereavement. Stajduhar, Martin, and Cairns (2010) carried out focus groups with bereaved family caregivers, who reported that the additional role they adopted as a cancer caregiver alongside their existing responsibilities (such as parenting), often led them to feel a pressure to be strong for everyone around them. They considered this to have been exacerbated by the disappointment they felt in the absence of support from friends.

#### 1.5.2.2 *Negotiations within the healthcare setting*

Participants who took part in Stajduhar et al.'s (2015) study spoke of the guilt they experienced as a result of missing the death, which they related to sudden and unforeseen changes in the patient's condition, or miscommunications by professionals regarding the prognosis. These experiences were considered to have impacted on their grief responses after the death. Furthermore, caregiving experiences that are associated with indignity or a lack of respect from medical professionals may result in distressing memories that negatively impacted on participants' perceived ability to cope in their later bereavement (Keegan, McGee, Hogan, Kunin, & O'Brien, et al., 2001). Dumont et al. (2008) found that the experience of the physical symptoms of cancer and the circumstances surrounding the death had an important influence on later bereavement. Specifically, participants perceived their loss to be more manageable when patient suffering was minimal, when dignity had been maintained and following

what was considered to be a peaceful death. In contrast, the deterioration and changes to behaviour or mood caused distress, which participants incorporated into their grief. In line with this, bereavement has been suggested as being influenced by the experiences involved in the terminal phase of cancer and the period of time just before the patient dies (Hudson, 2006). This has significant implications for the need for good support for relatives in palliative care settings (Mossin & Landmark, 2011).

#### 1.5.2.3 *Relationships and support*

Reports from family members highlight their increasing isolation during their caregiving experiences, which links to the burden of having to make decisions alone and the challenges involved in communicating with others in the family and medical professionals (Totman et al., 2015). Dumont et al. (2008) further illustrated how the support caregivers receive from friends and family and via their interactions with professionals served to decrease stress and anxiety during caregiving, which had positive implications for bereavement.

#### 1.5.2.4 *Positive aspects of caregiving*

In contrast, other studies have illustrated some of the positive experiences that have been associated with cancer caregiving. Participants who took part in Wong and Ussher's (2009) study reported being able to identify positive aspects within the context of their care. Themes within these interviews included the discovery of their own personal strength through adversity, being able to find acceptance in their situation, and an appreciation for the increased quality of their relationship with their dying loved one. In a later study, Wong et al. (2009) reported the perceived benefits that individuals may experience in being able to provide palliative care to their loved one at home, which enabled them the opportunity to be physically close to the patient, to ensure their comfort, and which was reported as facilitating the process of saying goodbye. These studies additionally draw attention to factors such as dying at home, which is frequently considered

to represent a way for carers to offer their loved ones a 'good death' (Sinding, 2003) by maintaining their dignity (Koop & Strang, 2003).

However, despite this, the majority of theoretical perspectives of grief and bereavement and the subsequent therapeutic practices these inform, have tended to remain largely acontextual, and infrequently differentiate cancer bereavement from loss due to other causes (Mackinnon et al., 2013).

Furthermore, whilst these findings draw attention to discourses such as the 'good death' described in Valentine's (2008) study, these concepts are not explored further in this research.

### 1.5.3 Discursive Approaches to Cancer

Of relevance to the current study, Willig (2011) takes a discursive approach to explore the dominant discourses that resource constructions of cancer in the UK, including to consider how individuals who are diagnosed with the illness can be positioned within these discourses and the consequences these have for their lived experiences. Here, Willig draws attention to the increasing media coverage of 'survivor stories' within the context of cancer, which, together with the widespread availability of material to promote healthy living and advice to prevent cancer necessitates a positive outlook whilst constructing engaging with the possibility of death as morbid. Consequently, she argues that those to be given a terminal cancer diagnosis may find themselves excluded from the dominant narrative of thinking positively and struggle to make sense of their experiences and alienated from others as a result. Through reflections of her own experience with cancer, Willig suggests that the dominant discourses surrounding cancer can also lead society to question the influence of an individual's lifestyle, including an assumption that they may have in some way done something to bring the cancer on.

These contextual factors may have important implications for the lived experiences of those who are bereaved specifically by cancer in comparison with

bereavement experiences following other causes of death and therefore build on the rationale to take a discursive approach to studying cancer bereavement.

## **1.6 Spousal Bereavement**

Grieving responses following the death of a partner or spouse may be particularly distressing compared with other bereavements (Parkes, 2006), with partners often reporting that they feel as though they have lost a part of themselves that existed within a shared identity (Bradbury, 1999). Lowe and McClement (2011) argue that the death of a spouse is both profound and life altering; perhaps due to the disruption of social roles following bereavement (Jakoby, 2012).

Traditionally, however, the literature surrounding the topic has been relatively limited to the grieving experiences of older widows (see Stroebe, 1993), which has attended to their increased risk of mortality following loss (Stroebe & Stroebe, 1993) and typically focused on risk factors for psychiatric symptoms (e.g. Gilbar & Ben-zur, 2002). In other words, it is reflective of the positivist framework outlined in section 1.3, which dominates much of the psychological research.

In a recent review of bereavement experiences in older adults, Naef, Ward Mahrer-Imhof and Grande (2013) highlight a number of other factors also considered to be pertinent within this context. These included disruption to everyday activities and routines and struggling to manage spare time (Anderson & Diamond, 1995). The review also drew attention to the pervasive loneliness frequently associated with the loss of a companion (Brabant, Forsyth & Melancon, 1992; Anderson & Diamond, 1995), and the challenges surrounding the continuation of life as a single person.

### **1.6.1 Age and Gender**

While the majority of studies have focused on older spouses, Lowe and McClement (2010) interviewed widows aged 45 and under and reported hearing

similar concerns about returning to a single status and navigating new romantic relationships. However, additional factors that were reported by this specific age category were anxieties about being a single parent and the loss of future hopes and dreams that related to this. This study further highlighted the perceived absence of support groups for their specific loss, in which they could talk about their experiences with other young widows. This raises important questions regarding the availability of support for specific forms of bereavement, suggesting more can be done to help those struggling with the loss of a partner. However it is acknowledged that this study may not be representative beyond the participants who took part in it.

As previously noted, the literature has typically reflected a female perspective on spousal bereavement (Naef et al., 2013). A minority of studies have focused on men's experiences, however. In Daggett's (2002) interviews they reported that the seeking of support represented a particular challenge for widowers, for whom support from friends was short-lived. Participants described struggling to share their bereavement experiences, instead tending to rely on problem-solving as a means of coping. The study further highlighted the extent to which men tried to control and suppress emotional responses in grief. In Brabant et al.'s (1992) study, only two out of seventeen male participants reported having reached out to others for support. Kaunonen, Päivi, Paunonen, and Erjanti (2000) additionally noted gender differences in the expression of grief in Finnish spouses, suggesting that whilst women tended to be more verbal about their feelings, men conveyed greater concern about feeling lonely. According to Martin and Doka (1996), revealing emotion and the seeking out of support are stereotypical of female grieving, however the cultural influences involved in this were not examined in these studies.

Despite the frequent reference to divergences in grief experience according to gender, the broader context to this remains relatively unaddressed in the research. However, the influence of cultural and historical factors relating to

gender may enable better understanding of how these differences have been shaped over time, and incorporated into theoretical perspectives of bereavement.

## **1.7 Spousal Bereavement and Cancer Caregiving**

The death of a spouse or partner to cancer may be a particularly challenging form of bereavement, due to the frequency with which spouses typically take on the caregiving role (Trudeau-Hern & Daneshpour, 2012; Caserta, Utz & Lund, 2013; Gauthier & Gagliese, 2012) and the corresponding stressors that this new and complex role often brings (Kim, Baker, Spillers and Wellisch et al., 2006). Furthermore, spouses are often required to adopt this role without much notice or time to prepare (Trudeau-Hern & Daneshpour, 2012). As a consequence, the alignment of spousal and cancer bereavement has become an increasing focus within the recent literature (see Fasse et al., 2014), much of which emphasises the increased psychological vulnerability within this population of people post-bereavement (e.g. Gilbar & Ben-Zur, 2002). In their quantitative study, Caserta et al. (2013) proposed that death expectedness may serve as a mitigating factor in subsequent spousal bereavement. Furthermore, they also emphasise that the specific experience of bereavement by cancer appeared to be associated with greater distress compared with unexpected death by other causes. In contrast, however, qualitative research indicates that the finality of death is experienced as shocking and overwhelming, regardless of how expected it was or the extent to which spouses felt prepared for it, (Agnew et al., 2008).

Gauthier and Gagliese (2012) suggest that the specific impact that bereavement has on spouses is not only due to the unique challenges in mourning a partner, but additionally following the loss of the roles they previously held as spouse and caregiver, respectively. Given reports that caregiving responsibilities were considered comparable to having a full-time job (Trudeau-Hern & Daneshpour, 2012), these losses may represent significant changes in their day-to-day lives.



In their recent and comprehensive review of cancer bereavement in spouses, Fasse et al. (2014) consider some of the key factors involved in the cancer trajectory that may impact on subsequent grief reactions in this population. This emphasises particular factors that have been focused on within existing research relating to the experiences within palliative care contexts and the role of caregiving during end-of-life. However, as is consistent within the broader bereavement literature, the authors draw attention to the predominance of quantitative research, much of which has focused on the theoretical conceptualisation of grief within a psychiatric context. This was a shared finding within the current review, in which research pertaining to the lived experiences of bereaved spousal caregivers represented a relative minority within the literature. Fasse and colleagues suggest that the dearth of qualitative research within this domain may be due to the perceived concern that taking part in an interview could cause participants greater distress than completing a questionnaire. Given some of the dominant discourses about grief and its expression that were outlined in section 1.4, this assumption may represent an interesting line of enquiry in understanding the broader context of bereavement and the impact this has on how it is studied. Fasse et al. (2014) conclude that further examination of the lived experiences of caregiving during end-of-life and subsequent bereavement is highly warranted in order to better understand this particular form of loss.

Research studies carried out using qualitative methodologies in order to explore the subjective experiences of bereaved spousal carers report findings that have considerable overlap with the literature examining cancer caregiving more broadly (as outlined in section 1.5). This includes feelings of isolation (Holtslander & Duggleby, 2010; Agnew et al., 2008; Trudeau-Hern & Daneshpour, 2012) and challenges within the palliative care context (Agnew et al., 2008). To avoid repetition, these findings will not be further explored here although of particular note, participants in Agnew and colleagues' study identified their social isolation to be greater when friends and family appeared to lack

insight into their loss, and in response to a perceived impatience within society about their continued grief. Some gender distinctions were reported in this study. For example men were reported as being more motivated to seek out new relationships and re-integrated more readily than females, despite reports of loneliness from both. Additionally, female participants in particular referred to their newly single status, reporting a struggle to socialise with other couples in their social networks.

Of particular interest, two studies have examined the transition from the role of caregiver to bereavement (DiGiacomo et al., 2013; Trudeau-Hern & Daneshpour, 2012). DiGiacomo and colleagues interviewed older female caregivers who were recently bereaved. They identified that participants in this position had frequently put their own poor health to one side in order to focus on their partner. Consequently, participants reported maintaining a façade of coping, whilst often suffering in silence. This is in contrast to other findings that women may be more likely than men to ask for help, and suggests that assumptions about female help-seeking behaviour may leave caregivers' needs unmet, which could influence their grieving response to the death. This study additionally highlighted the value that was perceived by participants in professionals who acknowledged the death and provided post-bereavement follow-up, illustrating the important influence that medical professionals may have on the transition into bereavement.

Trudeau-Hern and Daneshpour (2012) interviewed a mix of current cancer caregivers and widowers about their experiences, which attended to a number of experiences unique to spousal caregivers. Firstly, they highlighted an avoidance that was reported by a number of participants in discussing the terminal nature of the cancer and the implications this had for death, so as to prevent becoming emotional and causing upset to their dying spouse. However, those participants who held open conversations about this reported increased closeness in their relationship as a result, which may be influenced by dominant discourses relating

to the fear and avoidance of death and this has implications for how death is communicated between spouses.

Further, they explored the meaning of marriage to participants following the diagnosis of cancer. Whilst this revealed mixed responses overall, participants who were bereaved recalled their experiences of the final months before death as being more positive than those caregivers currently providing care. In comparison, bereaved individuals also recalled improvements to the quality of their marriage, suggesting that death impacts on how bereaved individuals make sense of their caregiving experiences. However, the wider influences shaping these experiences were not attended to in this study.

In summary, whilst these studies afford a greater understanding of the lived experiences of spousal bereavement in the context of cancer, the minority of discursive approaches within this area render the broad context surrounding these experiences comparatively unexplored. This contributes to the consistent theme throughout the review of the literature within this chapter, and points to the undertaking of research from this perspective.

## **1.8 Conclusions and Rationale**

In a review of the current literature, this chapter has highlighted how dominant discourses about bereavement carry powerful assumptions of universalism and prescriptivism, and the expectations for grief to 'run its course' within a certain time-limit (Breen & O'Connor, 2007). The increasing medicalisation of grief serves to pathologise individuals who deviate from what is considered 'normal' grieving, which has implications for its 'treatment' (Kleinman, 2012).

Fundamentally, the dominant conceptualisations of grief have important implications for power and locate expertise within professionals, which serves to disempower lay members of society (Hockey 2001). This may account for the reported avoidance of death, and inability for bereaved individuals to be able to

talk about their experiences within their usual support networks (Jakoby, 2014; Trudeau-Hern & Daneshpour, 2012).

Despite this, bereavement interventions are typically informed by the dominant ideas produced within the literature (Fasse et al., 2014), the majority of which are encompassed by a positivist paradigm that reinforces the increasingly medicalised approach to grief. Furthermore, as previously noted, bereavement support services tend to implement the traditional stage models (Payne, Jarrett & Wiles et al., 2002), which have received extensive criticism and may reinforce unhelpful assumptions for bereaved individuals.

Whilst there has been a recent rise in qualitative research seeking to understand grief and bereavement from the subjective perspective, the methodologies that have been typically employed tend to limit exploration to the content of subjective experience. In contrast, there is a significant scarcity of discourse analytic research that aims to examine the 'how' and 'why' involved within these experiences, and the broader influence of macro-level processes. Existing research from this perspective points to a societal role in grief constructions, and highlights the need for further investigation of the powerful discourses that surround the concepts of grief and bereavement.

Bereavement by cancer may be impacted specifically by the unique experiences associated with caregiving in the context of terminal illness; a role that spouses and partners frequently adopt. Given increasing incidence rates of cancer in the UK (Cancer Research UK, 2015), it seems likely that this population of people may present more frequently in clinical psychology contexts. The acontextual theoretical perspectives of grief within the literature however, reinforce assumptions of universality, and therefore fail to capture the specificity within this type of loss (Fasse et al., 2014), or account for the wider discourses that inform how spousal bereavement following cancer is constructed within society.

Exploration of the discursive factors influencing how those bereaved by cancer construct grief and loss would add to the small number of bereavement studies carried out from this perspective. Furthermore, the findings could be used to inform how intervention services are developed and may have important implications for the ways in which services, and society in general, respond to and support the experience of this phenomenon.

#### 1.8.1 Aims

There is a need for further investigation of how grief, bereavement and losing a loved one to cancer is constructed through interactions between people, as well as how social and historical discourses shape this process. By attending to these gaps in the literature, the current research aims to gain a richer understanding of the complex interplay between subjective experience and social practices.

The following research aims to contribute to the explorations made from a discursive perspective as outlined above, in order to address the following research questions:

#### 1.8.2. Research Questions

How do people who have lost their spouse/long-term partner to cancer construct their grief and loss?

- What are the dominant discourses that are drawn upon in people's constructions of cancer bereavement?
- How do these discourses position individuals and with what consequences?

## **2. METHODOLOGY**

This chapter provides an explanation of the epistemological positioning of the study (including its particular relevance to the topic) and outlines the theoretical rationale guiding my choice of methodological approach. Details about the service context in which the research took place and the strategy for recruitment and data collection process are also described. Finally, consideration is given to the key ethical issues involved in the development of the research.

### **2.1 Epistemological Position**

Epistemology, or the theory of knowledge, seeks to address the question of “How, and what, can we know?” (Willig, 2013, p. 4) and relates to the claims that can be made within the context of research. By adopting a particular epistemological position, researchers are able to outline their assumptions as to what it is possible to know about reality, allowing the particular claims that are made in qualitative research to be evaluated by others (Harper, 2012).

The current study adopted a social constructionist-critical realist epistemology. Rather than capturing a single description or definition, social constructionism encompasses a breadth of psychological and sociological approaches that are unified by four key assumptions. These propose “a critical stance toward ‘taken for granted’ ways of understanding the world; [that] concepts, constructs and knowledge are sustained by social processes and are historically and culturally situated; and [that] knowledge and social action go together” (Gergen, 1985 in Burr, 2003, p. 2-5).

Social constructionist research is therefore concerned with the constructed nature of social reality, examining the ways in which particular phenomena (such as grief and the loss of a partner due to cancer) are constructed through discourse, and how this informs the subject positions made available within

society. Since knowledge is assumed to exist as a result of language, non-discursive phenomena are considered of secondary importance to researchers (Sims-Schouten, Riley, & Willig 2007). At its extreme, radical or 'strong' social constructionist researchers propose that 'there is nothing beyond the text' (Edwards & Potter, 1992). However, such pure relativist assumptions have been criticised for failing to account for the material and physical nature embedded within human experience (Cromby & Nightingale, 1999). So-called 'weaker' forms of social constructionism acknowledge that while language facilitates how we make sense of our social realities, such constructions are constrained by the possibilities that exist within the material world (Sims-Schouten et al., 2007). The integration of social constructionism and critical realism has been described as ontologically realist but epistemologically relativist (Harper, 2011). Such critical realist social constructionist positioning allows for further interpretation of the data, enabling researchers to make ontological claims about the impact of the material on the discursive (Willig, 1999). Since the material phenomena of death and dying are fundamentally associated with the constructions of grief and bereavement, adopting this position within this study acknowledges the materially 'real' nature of loss upon which discourses are socially constructed.

## **2.2 Methodological Approach**

This study takes a qualitative methodological approach (which attends to meaning and subjective experience as opposed to establishing cause and effect relationships) to explore how individuals who have lost a spouse to cancer construct their experiences. Furthermore, given the study's particular interest in discerning how participants use language to construct their experiences, and how the broader social context serves to resource this, a discursive approach was deemed as being more appropriate than other, non-discursive methodologies, which by attending more to the content of subjective experience would not achieve the study's aims. For example, Interpretative Phenomenological Analysis (IPA) pays particular attention to how individuals experience a given

phenomenon, by focusing on their thoughts and feelings, and in the nature and quality of what they say (Willig, 2013). Epistemologically, then, IPA makes claims about the possibility of gaining access to an individuals' internal world in order to gain an understanding of their lived experience (Smith, Flowers, & Larkin, 2009). Whilst these factors are of interest to the aims of the current research, adopting a phenomenological approach would not enable examination of the broader mechanisms influencing how experience is constructed, and was therefore ruled out in this study. Given this interest in the discursive, other qualitative approaches such as Thematic Analysis and Grounded Theory were also discounted.

#### 2.2.1 Consideration of Alternative Discursive Approaches

During the process of deciding on a suitable methodology for this research, Narrative Analysis also appeared to be able to address the aims of the study, given its epistemological position. Narrative approaches also produce social constructionist knowledge and enable examination of dominant narratives within society (both on macro and micro levels), and how these may be taken up or resisted to story individual experience (Riessman, 2008). Despite this, FDA was deemed most appropriate for the aims and design of this study, particularly given that implementing a Narrative Analysis may require the compromise of using a very small sample size to present individual accounts and regarding decisions made around data collection (see section re focus groups). FDA is also aligned with the social constructionist epistemological position that is outlined in the previous section, which states that social phenomena and their associated meanings are constructed via language.

#### 2.2.2 Foucauldian Discourse Analysis

As previously noted, discursive methodologies are particularly concerned with the role of language in constructing meaning and discursive practices. Broadly speaking, discourse analysis is concerned with language and the ways in which it constructs (as opposed to mirrors) reality (Georgaca & Avdi, 2012). Amongst the



increasing range of alternative methodologies within discourse analysis, Harper (2006) distinguishes between two principal approaches that seek to address subtly distinct research questions; discursive psychology approaches (e.g. Potter & Wetherell, 1987) and Foucauldian Discourse Analysis (Willig, 2001; Arribas-Ayllon & Walkerdine, 2008), which is informed by post-structuralist ideas and the work of Michel Foucault.

Whilst both are concerned with the use of language, FDA is considered to be a 'macro-level' approach because it enables the researcher to move beyond the immediate rhetorical level of language (and its influence on social interaction) to consider how particular constructions are located within institutional contexts and made more or less possible by the availability of discursive resources (Willig, 2013). In contrast, discursive psychology is considered a 'micro-level' approach because it takes account the performative nature of discourse (Holt, 2011). FDA is further concerned with how these constructions offer certain subject positions and practices, and how privileged positions may be taken up or resisted to inform subjective ways-of-being (Willig, 2001). In the current research, adopting a Foucauldian approach to the analysis enables identification of the dominant discourses that operate in the context of loss and bereavement, and examination of the subject positions taken up by participants as a consequence of these.

### 2.2.3 Foucault's Approach to Power

A further focus of FDA is the role of discourse in the broader context of power and the processes of its legitimation within social structures (Willig, 2001). Foucault theorised that "Power is everywhere: not that it engulfs everything, but that it comes from everywhere" (Foucault, 1978, p. 93.). As such, power is understood to exist between people and institutions, and as being represented within and disseminated via discourse, knowledge and 'regimes of truth', which Foucault termed 'power/knowledge' (Foucault, 1977).

In addition to its repressive capacity within the context of social control, Foucault conceived of power as additionally having productive aspects in the form of resistance whereby alternative (and more subjugated) truths can also be voiced via counter discourses. Foucault, suggested that resistance of dominant discourses serves to undermine accepted truth claims and opens up alternative ways-of-being, which in turn has implications for the possibility of alternative social practices.

## **2.3 Procedure**

### **2.3.1 The Service Context**

Participants were invited to take part in this research via a registered charity that provides regular support to individuals bereaved by cancer (referred to as the service throughout). Monthly support groups and informal social events are held on a drop-in basis, and additional online support is provided via its interactive website. The service was set up in 2011 in the absence of any existing support for this specific type of loss. The current study is one of a number of different research projects undertaken by the service in order to better inform bereavement support.

This is a service that I have been involved with in a voluntary capacity for a number of years. My connection and the specific nature of my role within the organisation will be further explored in a later section.

### **2.3.2 Recruitment**

My pre-existing link to this service provided me unique access to large numbers of the relevant population and provided the basis for an opportunity sample. All but one of the participants recruited for the current study had previously sought direct support from the service, either by requesting specific information or receiving face-to-face group support. One individual had been forwarded details of the study via a friend already on the service's mailing list.

Following ethical approval from the University of East London and local permission granted by the service's Board of Directors (see Appendices B and C), initial information about the study was advertised on the service's website and social media pages and via electronic newsletter to those on the charity's regular mailing list. Interested participants were signposted to an online questionnaire that comprised a short number of questions relating to details of their bereavement (Appendix D). Here, they were additionally asked to give confirmation of their interest in the study and provide details of their preferred method of communication. I contacted individuals once I had received their completed questionnaires to confirm their interest and availability to participate. At this point all participants were sent electronic copies of the information sheet, which contained further explanation about the purpose of the study (Appendix E), the consent form (Appendix F) and information about the venue and travel.

### 2.3.3 Participants and Inclusion Criteria

In order to be included in the research, participants needed to identify specifically as experiencing the death of their spouse or partner due to cancer. Since my focus for the research was on adult populations, participants were also required to be over the age of 18. I requested that participants confirm this information within the short questionnaire they completed at the point of registering their interest. Given that the study aimed to capture conversations between participants, they were also required to have a good level of spoken English to facilitate discussions within the group.

I decided not to place any constraints upon the amount of time passed since spouses/partners had died, or to exclude those very recently bereaved from taking part. Whilst this decision had important implications for the potential distress that taking part could lead to (and therefore required careful ethical consideration), I wanted to avoid making the assumption that the longevity of bereavement would necessarily mean that individuals felt less distressed about their loss. This was partly informed by my observations in facilitating

bereavement support groups, in which attendees frequently report the expectation that 'time is a healer' as being unhelpful.

#### 2.3.4 Participant Demographics

A total of twenty-three participants took part in the study. Focus Groups 1 and 2 took place on the same day and comprised 7 people respectively. Focus Group 3, carried out approximately two weeks later comprised 9 people. Across the three groups there were six men and seventeen women aged between 34 and 72 (mean age was 53.35). All participants identified as being heterosexual. Table 1 contains the demographic information provided by all participants, each of whom were assigned a pseudonym in order to protect their anonymity.

Pseudonym	Gender	Age	Ethnicity	Religious affiliation	Person who died	Time since death (Years: Months)	No. years known for
<b>Group 1</b>							
Keith	Male	62	White British	Buddhist	Wife	5:5	32
Andrew	Male	52	White British	None	Wife	0:3	22
Mary	Female	52	White Irish	Roman Catholic	Husband	3:9	29
Anna	Female	60	White British	None	Husband	0:4	13
Sarah	Female	58	White British	Church of England	Husband	3:0	20
Lucy	Female	34	White British	None	Husband	3:2	3
Jan	Female	64	White British	Christian	Husband	2:5	39
<b>Group 2</b>							
Paul	Male	68	White British	Roman Catholic	Wife	0:11	44
Linda	Female	53	White British	None	Husband	2:6	23
Christine	Female	57	White British	Atheist	Husband	7:11	20
Aanya	Female	53	Indian	Hindu	Husband	3:10	33
Catherine	Female	53	White Irish	Born Catholic now atheist	Husband	4:3	20
Dave	Male	51	White British	None	Wife	2:11	28
Robert	Male	67	White British	Roman Catholic	Wife	2:9	12
<b>Group 3</b>							
Kate	Female	52	White British	None	Husband	1:4	22

Neela	Female	57	Asian British	None	Husband	2:4	31
Marion	Female	55	White British	None	Husband	2:0	30
Gill	Female	51	White British	Church of England	Husband	1:1	24
Angela	Female	51	White British	None	Husband	0:8	24
Philippa	Female	55	White British	None	Husband	3:10	25
Karen	Female	53	White British	Church of England	Husband	0:4	35
Scott	Male	43	White British	None	Wife	0:6	24
Diana	Female	72	White British	None	Husband	1:3	25

Table 1. Demographic profile of participants

### 2.3.5 Service-User Consultation

Incorporating service-users within the process of research can help encourage the generation of alternative, in-depth knowledge within the mental health context (Ramon, 2000). In order to afford representatives of this population the opportunity to voice their reflections and opinions or any concerns about the study, three beneficiaries of the service were recruited via the charity's social media to act as consultants to the research process. This group comprised two women and one male, all of whom identified as having lost their spouse or partner to cancer. This process entailed conducting a brief informal telephone interview with each consultant. Feedback was sought about the rationale for the study, (including the research questions) and its perceived relevance for this population, the written information about the research intended for participants and an overview of the interview schedule and agenda for each focus group.

Overall, all consultants felt that the study was highly relevant for spouses/partners who are bereaved by cancer feeding back that the broad topics I had proposed to cover were both important and appropriate. One consultant voiced his particular interest in the impact of the wider context on an individual's experience of grief.

Another issue raised during this process was the manner in which distress in response to the content of the discussion would be managed during each group. Following discussion with one of the consultants, this feedback was incorporated into the decision to provide an additional private space for people to use should they need to leave the discussion. This issue will be revisited in section 2.5.3.

## **2.4 Data Collection**

Data were collected via focus groups that were digitally recorded and transcribed for analysis. Three separate groups were carried out in accordance with guidance relating to the point of data saturation in focus groups (Howitt, 2010). This method of data collection was deemed particularly appropriate given the specific aims of the research. Unlike individual interviews, data collected within a group enables examination of the interactions between participants, providing further insight into how people co-construct grief and bereavement (Willig, 2013). The epistemological position of the research implicitly considers the researcher as active and involved, acknowledging the impossibility of neutral observation (Burr, 2003). However, the dynamics within a group context decrease opportunities for the researcher to influence discussions, placing more emphasis on the voice of the participant (Frith & Gleeson, 2012).

All focus groups took place in a private room at one of the University of East London sites. I decided to avoid using any existing venues used by the service in an attempt to encourage participants to differentiate between a typical support session and the research context of the focus groups. Prior to commencing the session participants were asked to re-read, sign and date a consent form. Each session lasted approximately two hours and began with a short welcome and introduction that was not recorded. Here, I gave participants an overview of the session and explanations about my role as the researcher and the supporting role of the representative from the service. A number of group 'rules' were introduced to further ensure participants' sense of safety and effective running of

the group. These included maintaining confidentiality, respecting differences within the group and ensuring that all mobile phones were turned off. In preparation for the three groups, I developed a broad list of themes (see Appendix G) based on my research questions to help in generating discussion. However, I encouraged participants to set their own agenda and speak about the issues and experiences considered pertinent to them. The initial question that I posed to each group was deliberately broad and open-ended to avoid influencing subsequent conversations in a particular direction.

I stopped recording just before the end of the session to provide participants with a short debrief, which included giving them the opportunity to ask questions. I encouraged people to contact me with any concerns or queries about their participation and informed them that I would provide them with feedback about the outcome of the study when it was finished.

## **2.5 Ethical Considerations**

Ethical approval was granted from the School of Psychology Research and Ethics Sub-committee at the University of East London (Appendix B) Additional permission was sought from the service's Board of Directors (Appendix C). Given that all recruitment took place via a voluntary sector organisation, NHS ethical approval was not required.

### **2.5.1 Informed Consent**

Given that participants were invited to speak about potentially intimate and highly sensitive emotional experiences, it was important to ensure that they were fully aware of this and understood their role within the focus groups so that they could give their informed consent. This was particularly important given the decision not to exclude individuals on the basis of how newly bereaved they were. Participants were invited to raise questions or concerns at the beginning and end of each focus group. I reminded participants of their right to withdraw from the

study with no disadvantage to them following this decision. Due to the method of data collection, I explained that it would not be possible to remove individual data from the audio recording but that direct reference to this could be avoided in the write up. No participants requested to withdraw.

### 2.5.2 Confidentiality and Anonymity

Participants were informed that their personal information would be kept confidential and be securely stored on a password-protected computer. Before the start of each focus group, participants were invited to provide the group with their first name so as to aid their discussion. The issue of maintaining one another's confidentiality was also addressed in the ground-rules that were established at the beginning of each session. In order to protect anonymity following data collection, identifiable information including the names of participants and their partners were changed during transcription. During one of the focus groups, one participant requested that the name of a service be kept confidential. Upon reflection of this, I decided that other pertinent details relating to patient care and the time of death would be additionally anonymised out of respect for confidentiality. Access to the transcribed material was limited to supervisors and examiners and I was the only person who listened to the audio recordings.

### 2.5.3 Support for Participants

In acknowledgment of the sensitive and potentially distressing nature of the study, it was agreed that a member of the service would be available at each focus group to offer information or provide support to anyone who became distressed. This included reminding people about the support available through the current service, as well as providing information about alternative support such as The Samaritans. It was noted that the member of the service would follow anyone who became distressed and needed to leave the room. While a number of people did become distressed during the sessions, no participants left the discussion, or voiced wishing to do so. An explanation about the support



member's presence and the specific purpose of their role was clearly provided before the session began and the support member was sat outside the circle to reiterate that they would not be taking part in the focus group itself.

#### 2.5.4 The Dual Role of the Researcher

I have been involved in the creation and development of this specific service on a voluntary basis since its creation in 2011. During this time I have occasionally facilitated monthly support groups and sit as a member of the board of trustees. Recruiting from a known service ensured a sense of familiarity, which may have positively impacted on the recruitment process. However, this may have made it more challenging to introduce myself in a new role, especially given that I had previously met some but not all of the participants in a therapeutic capacity. Ethically, it felt crucial to be transparent with participants about the implications for my shifting to the role of the researcher in this context and this was explicitly outlined at the beginning of each focus group. On further reflection, having a service representative present during each focus group further served to differentiate my role as researcher.

### **2.6 Reflexivity and The Researcher's Position**

Rather than being considered a neutral observer, as reflected within a positivist framework, social constructionism positions the researcher as subjectively co-producing knowledge within the data they collect (Silverman, 1997). Reflexivity is therefore an important process within qualitative research as it encourages the researcher to reflect on the ways in which they influence and shape how the research develops and the conclusions they will draw from the data (Nightingale and Cromby, 1999). Personal reflexivity enables the researcher to reflect on how they contribute to the research as individuals (Willig, 2001) and acknowledges the intersubjectivity between researcher and participants (Valentine, 2008).

Inevitably then, my own personal and professional experiences informed the development of this research. From a personal perspective, I am a white British woman in her thirties carrying out this study in the context of my professional doctoral training in clinical psychology. The inspiration and initial thinking behind the current research was largely informed by my involvement in the collaborating organisation and the accounts I had already heard shared by those bereaved by cancer. The absence of any significant experience of bereavement in my own life, particularly the death of a partner due to cancer will necessarily impact on the interpretations I make from the data. Nevertheless, listening to people's experiences has shaped my constructions of death, loss and grief and afforded me greater insight into the broader assumptions surrounding these phenomena within society. In particular, I have been repeatedly struck by the powerful social isolation that often occurs following the loss of loved one, linked to which is the apparent absence of helpful support or communication from family or friends, or the wider community in general. My observation that many bereaved people appear to find benefit in being able to talk openly about death and grief with others has often led me to consider the potential cultural barriers that impact the experience and expression of bereavement.

In the context of my professional development, my experience of clinical training has exposed me to 'alternative ways of knowing' and encouraged me to question the assumptions that underpin taken-for-granted concepts by acknowledging their historical political and cultural roots. My developing appreciation for critical thinking has had an influence across a range of areas in my personal and professional life, including the approach I have taken in the context of this research. As a developing clinician, and of further influence, I have been subjected to a range of psychological theories, which have shaped the way in which I understand human behaviour and the meaning that I attribute in my observations.

So as to maintain reflexivity throughout the process of research, I made use of a reflective journal (Finlay & Gough, 2003), in which to reflect on important issues such as my own experiences of facilitating the focus groups and the subsequent thoughts I had about the discussions that took place within them during the processes of analysis.

## **2.7 Data Analysis Process**

### **2.7.1 Transcription**

I transcribed all three focus groups verbatim. Engaging in this enabled me to become more familiar with the data and allowed more reflection on my role as the researcher and served to initiate the process of analysis (Bannister, 2011). Transcribing conventions were adapted in part from Malson (1998) and can be found in Appendix H. A simplified transcription was used since the focus of the research was not explicitly to examine the use of rhetorical devices or patterns of speech, but more on broader discursive constructions (Malson, 1998). Participants were identified in the transcripts by their pseudonym.

### **2.7.2 Approach to Analysis**

I read through each transcript several times in order to familiarise myself with the respective conversations that had taken place in each group, together with the individual accounts given by the participants within them. In the absence of any clear delineation from Foucault as to how to conduct an FDA (Graham, 2005), the approach I took in the analysis was informed by Willig's (2001) six-stages for identifying discourses together with considerations outlined by Arribas-Ayllon and Walkerdine (2008). For clarity, these were represented distinctly using a colour-coding system (see Appendix I for a worked illustration of this). Arribas-Ayllon and Walkerdine suggest that whilst FDA typically operates at the macro-level of discourse, further examination of the linguistic and rhetorical devices that are operationalized within conversations may benefit the interpretation, provided the wider historical and political context is not lost from this process. In line with this,

and given my decision to conduct focus groups as opposed to individual interviews in order to explore participants' co-constructions of grief and loss, I decided to incorporate examination of the 'micro-level' of discourse. Each 'stage' of my analysis is presented sequentially below, however it should be emphasised that as an iterative and recursive process, the analysis involved continual inter-changing between these stages.

- Stage 1: Discursive constructions of grief and loss

A key element of my analysis concerned identifying the different ways in which grief and loss was talked about within participants' accounts. This included both the explicit and implicit references to the discursive objects.

- Stage 2: Discursive resources

This stage involved locating the wider discourses that informed and influenced participants' constructions, paying additional attention to the ways in which multiple discourses competed within constructions.

- Stage 3: Subject positions

This involved examining the subject positions that were produced as a consequence of these constructions. Rather than serving as a particular role, subject positions enable certain perspectives from which to view reality.

- Stage 4: Subjectivity

This aspect of the analysis involved identifying how the resourcing of certain discourses created possibilities for participants' subjective experience, such as how they were enabled to think and feel.

- Stage 5: Technologies of self and power

This stage involved identifying the way in which participants' accounts alluded to 'technologies', which refer to forms of social and material practices that reinforce power differentials through regulation and monitoring, via institutions or within the individual.

- Stage 6 – Action Orientation

Consideration of action orientation within the accounts involved attending to the way in which particular constructions achieved specific functions for the speaker and the implications this had within the focus group context.

- Stage 7 – Enacting of power

This attended to the ways in which power was enacted within speakers' accounts, which had implications for subject positioning and highlighted how the inherent power that is held within institutions can be maintained via discourse. See section 2.2.3 for an overview of Foucault's approach to power and as conceptualised for the purposes of analysis.

- Stage 8 – Linguistic techniques and rhetorical devices

Throughout the analysis, additional attention was paid to the ways in which rhetorical devices were employed within the accounts to produce micro-level discursive practices. This also involved consideration of the implications these techniques had within participants' discussions. Identification of rhetorical devices was informed by Potter (1996).

Having attended to each of the stages outlined above, I identified common discursive 'sites' within the data, which appeared to account for the range of constructions that were made by participants across the three transcripts. I made sure to repeatedly return to my specific research questions throughout the process of analysis to ensure these were being adequately addressed. I selected extracts according to how well I felt they represented the discursive constructions that I had identified. The outcomes from the analysis will be presented and discussed in the next chapter.

### 2.7.3 Implementing a Foucauldian 'Tool-Box' Approach

Rather than representing a systematised and prescriptive set of ideas, Foucault's work is the result of his changing thinking over time, and can therefore be understood and applied in numerous different ways (O'Farrell, 2005). Foucault

himself famously stated “I would like my books to be a kind of tool-box which others can rummage through to find a tool which they can use however they wish in their own area...” (Foucault, 1974, as cited in O’Farrell, 2005, p. 50). It is with this intention that I have approached this analysis, applying my understanding of his key principles to the study of bereavement. My interpretation of these will be incorporated where I consider them relevant in the next chapter. However, an outline of the key concepts informing this study can be viewed in Appendix J.

### **3. ANALYSES AND DISCUSSION**

In this section the key findings that arose from the analysis will be presented, discussed and linked to relevant wider literature, in order to address the specific research aims that were outlined in chapter one.

In order to address these, I have structured the analysis into three key discursive sites that were identified within the data. Extracts from the focus group transcripts will be used to illustrate how these different discourses render speakers' constructions possible, the subject positions and social practices they enable, and the implications these processes have for the operation of power. Consideration of the micro-level rhetorical devices employed in speakers' talk about grief and loss, and the consequences these have in the conversations will also be discussed.

Despite their discrete presentation here, it is important to state that the discourses described were considered to co-exist and overlap, producing tensions and conflicts as participants drew on competing resources in their talk. Whilst these discourses were identified as particularly pertinent and commonly drawn upon by the speakers in the group, their presence here is a result of the decisions I have made following my own subjective engagement with the data. Given its epistemological positioning, the interpretations I make within this study are subject to my own perspective and as located within my own culture and experience (as highlighted in the previous chapter). An alternative perspective, therefore, may lead to different interpretations, and would thus be reflected differently here. Further issues relating to subjectivity and reflexivity will be addressed in the next chapter.

### 3.1 Addressing Speakers' Constructions of Grief and Loss

Chapter one highlighted the subtle distinction in meaning between the terminologies of 'grief' and 'loss' such that grief refers to the emotional response to death and loss is the absence inherently involved in death (e.g. Jakoby, 2012). However, it was also noted that these terms are frequently un-differentiated in lay language, with terms that were encompassed under the umbrella term of 'bereavement' employed inter-changeably in society. To avoid making any assumptions on this basis, the research aimed to identify participants' constructions of grief and loss so as to capture any nuances that arose in how these terms were used during the discussions.

Whilst the loss was frequently constructed in terms of the person, future plans and the roles that people had adopted as partner or caregiver, my analysis of the data highlighted the ways in which participants' predominantly constructed grief and loss inter-changeably and as mutually fulfilling factors inherent in their experiences of bereavement. For example, where participants spoke specifically about the loss of their partner, they drew on their emotional response to this and visa-versa, as the following extract demonstrates.

Extract 1 (FG2): Lines 397-401

Paul            the main thing is the loss of her (.) not – unbelievable grief over feeling I can't see her again loss of all that companionship and all that - the second thing is the loneliness (.) and the loneliness to a great extent is a separate issue (.) even though it's obviously completely interlinked

Here Paul makes a distinction between loss and loneliness, the reasons for which he later goes on to evidence by highlighting that "there are solutions to loneliness but there isn't a solution to the loss" [line 406]. However, he also



acknowledges the inter-connectedness of these constructions, referring to the material reality of death as the “unbelievable grief” he experiences in response. Other speakers in the groups drew on the comparison between loss and feelings of loneliness [Angela, FG3: Lines 560].

As a reflection of this, I took the decision to address the two phenomena together throughout the analysis with their presentation as occurring interchangeably in the extracts included.

### **3.2 Medicalisation of Grief**

This section will examine the ways in which speakers drew on dominant biomedical discourses in their constructions of grief and loss. As highlighted in chapter one, the powerful shift towards a medicalised framework within Western society is rooted in the broader construction of modernity, the key tenets of which privilege assumptions of rationality and prescriptivity (Small, 2001). A biomedical framework conceptualises emotional distress as ‘mental illness’ for which medical ‘symptoms’ can be identified through diagnosis and treated through the application of psychiatric and psychological techniques.

Chapter one highlighted how the dominance of such discourses has resulted in a medical approach to grief that has informed lay understandings within society. In line with this, the conversations that took place within this study strongly reflect the power that is held within medical and psychiatric institutions and the implicit assumptions this has for the management or ‘treatment’ of grief and the associated social and professional practices. The medicalisation of grief in this study has been organised into two discursive sites: ‘symptoms and disorders’ and ‘the professionalisation of grief’.

### 3.2.1 Symptoms and Disorders

Extract 2 (FG2): Lines 609-638

Christine            It should be checked out for PTSD (...) I was treated for fourteen months for PTSD couldn't stop playing (.) the hospice scenario in my mind like a film and I announced it to the therapist myself you know I feel like I've got the smells <hmm> I'm in a film or a bit surreal (...) I did a lot of drawing out um our therapy and I found that sort of useful that somebody had addressed it [?] (...) because it's very old fashioned grieving bereavement (.) those terms and I did feel totally traumatised by it – watching somebody sink for five years (...) it's very very traumatising (.) cancer, it just has its own peculiar (.) sort of journey

Christine's account constructs her experience of grief in terms of symptoms of trauma associated with post-traumatic stress disorder. The assignment of grief as a category within the DSM carries powerful assumptions of abnormality (Harris, 2007), which result in the subject position of 'mentally ill'. Foucault (1977) proposed that the pathological categorisation of a particular section of the population enables the social control of the population, via powerful deficit discourses and technologies of normalisation. As such, the DSM represents a technology of power, which reproduces individuals as subjects of 'medical gaze' (Foucault, 1976).

The legitimisation Christine is afforded via the power of diagnosis is further acknowledged in her account when she states, "it was useful that somebody addressed it", which, enables her to feel that this is both a necessary and helpful diagnosis to have been given and locates the management of grief within professional 'treatment'. However, when she states that she "announced it to the therapist [herself]", Christine is enacting a technology of the self, by engaging in

self-surveillance and reproducing power via her own self-government (Foucault, 1978).

Whilst grief was additionally constructed in terms of depression and anxiety by other speakers, Christine's account of PTSD draws on more recent medical discourses of 'complicated grief disorder' and 'prolonged grief disorder', both of which reflect developments within the scientific study of grief. Christine's statement that "grieving bereavement" is "very old fashioned" is particularly powerful, as it indicates that understandings of grief (particularly following cancer) have moved on to become more accurately accounted for by a trauma paradigm. This is resourced by scientific discourses that are underpinned by an essentialist paradigm and constructs grief as developing in accordance to scientific progression. The power with which scientific rationale is reproduced in this extract could be seen as constituting a technology of 'scientific development'.

Christine constructs death following cancer as "very very traumatising", applying stress and repetition in order to emphasise her point, and to differentiate cancer bereavement from other forms of grieving. Despite the pathologised positioning that Christine is subjected to, drawing on a medicalised framework of trauma additionally allows her to be positioned as a victim of cancer.

In her study, Valentine (2008) described how discourses relating to the need to ensure a 'good death' during illness and in the dying process enabled her some of her participants to feel that they could have done more for their dying loved ones and became the source of continual regret and guilt. Within this study, Christine constructs her husband's death as dehumanising as evidenced in the extract by "watching someone sink for five years" which may also be resourced by the 'good death' discourse. If this were the case, drawing on the trauma discourse may have the potential to absolve Christine from any of her own feelings of guilt or as responsibility for the nature of her husband's death.

### 3.2.2 Time as Perspective

Participants within all three of the focus groups identified themselves according to the length of time that had passed since their partner had died. According to Small (2001) time is a “quintessential[ly] modernist construct” that is firmly rooted in its dominant assumptions about progression and reason (p. 40). As a consequence, assumptions of sequential time form the fundamental basis of the majority of existing models of bereavement and grief (Meyerhoff, 1982), and via association with the notion of prescriptivity, are implicit in the medicalised framework. As resourced by this assumption, a common saying often drawn upon in the context of loss and bereavement, is the phrase ‘time’s a healer’, which was referred to by one of the speakers (Sarah; FG1; line 242). The following extracts explore how time was incorporated into participants’ constructions of grief and the effects that were achieved as a result.

#### 3.2.2.1 *Time as identity*

Extract 3 (FG1): Lines 51 – 83

Lucy            you know, it would be kinda like every minute you’d just feel awful and then that would kind of go to every five minutes and then it would go to every hour and then it would go to every few hours and eventually you might be able to get - <hmms> through a day and feel alright about it, you know? And um, and I’m – I’m three years – it’s just gone three years, so um, and it’s it’s – yeah – it does get – it has got much (.) much bigger, the time between feeling really sad  
[25 lines missing]

Anna            I think I – I just haven’t got the perspective of three years or five years. It was about four and a half months ago I um, my husband died, um, so I feel I I’m still I’m still in a – in a in a fairly depressed stage at the moment

These accounts demonstrate the assumed correlation between longevity in bereavement and notions of progression and improvement. In the first part of Lucy's extract, her construction of grief as improving with the passage of time itself takes a sequential, chronological format, which serves to reinforce both the prescriptivity of grieving and the dominance of time as a framework in which grief is conceptualised. Lucy's statement that "I'm three years" locates time within her identity, which was representative of how many of the speakers in the study introduced themselves into the discussions. In some cases this information was given as a substitute for their name and as such, represents a discursive practice in talking about grief. As a consequence, this functioned as a marker to the other griever in the group, by producing a certain 'status' of bereavement from which assumptions could be made as to 'where they were' in their grief.

This is evident in Anna's account where, in comparison to Lucy, she relates her relative lack of "the perspective of three years or five years" to being in "a fairly depressed stage", which is resourced by discourses about prescriptivity and alludes to the dominant assumptions held within traditional stage models of grief. Anna's talk produces respective subject positions of experienced and inexperienced in grief, according to the perspective that is afforded to individuals with time. This is further explored in the next section.

### 3.2.2.2 *Time and expertise in bereavement: resisting 'resolution'*

Extract 4 (FG1): Lines 2616 – 2618

Andrew        Yeah, I was quite relieved to hear of other people who've who are much more into it, have still got the grief 'cause it's always a fear of losing the grief as well

Here, Andrew conveys a sense of the anxiety he experiences in response to the expectation of resolution in grief. The use of the word "relieved" positions those individuals in the group who are "much more into it" as experienced, locating

expertise in those further on in the process. Correspondingly, in his position of inexperience in grief, he is afforded reassurance by the insight that is provided in their claims to “still [have] the grief”.

In this extract, Andrew constructs grief to be something you either have or do not have, which is indicative of the binary systems operating within scientific and biomedical frameworks. However, by constructing his “fear of losing the grief”, he is implying that to ‘keep’ grief is preferable to resolving it, which directly opposes the dominant assumptions of ‘recovery’ implicit within medicalised frameworks. Constructing grief in this way reproduces discourses of continuing bonds and enables Andrew to resist the expectation for him to ‘move on’ from his grief.

### 3.2.3 Professionalisation of Grief

Within some of the accounts, grief was constructed in terms of the professional support participants had sought, which placed responsibility for the management of grief within the professional domain. This relates to Rose’s (1985) ‘psy-complex’ theory, which is based on Foucauldian principles around surveillance and the regulation of society, and through which power is enacted via the dissemination of professional knowledge. This section will examine how the reproduction of psy-knowledge means that responsibility for and the control of grief is located within specific disciplines in order to regulate individual behaviour, and how the hierarchy that operates between distinct professional ‘knowledges’ has implications in terms of what kind of support is made available to individuals.

#### 3.2.3.1 *‘Treating’ grief: hierarchies of professional knowledge*

A number of participants’ accounts highlighted how the construction of grief as a psychiatric disorder led them to turn to medical treatment for the ‘symptoms’ of grief they were experiencing.

Extract 5 (FG2): Lines 1252-1260

Paul            I didn't want to take any antidepressant or anything and in fact I was seen by the psychotherapist at the hospice, who thought things like that were a mistake that you just go through the grief and then you get through it (...) you just go through the hell and what's the point of an antidepressant because um you'll get dependent on it and then when do you come off it (.) but I recently – I reached rock bottom and I (.) jumped ship and I found a bereavement counsellor for some one-to-one (...) who did me a questionnaire and said "look you're seriously depressed, you've scored X Y Z go and see the GP"

Paul's account highlights the divergence between psychotherapeutic and psychiatric conceptualisations of grief and the respective assumptions these make for its management. Via Paul, the former constructs grief as a necessary process that must be gone through, after which an end-point to the grief is implied. This view is reflective of traditional stages and phases models of grief (Kubler-Ross, 1972; Worden, 1991) and is positioned in opposition to the medical overlap between grief as depression in this account. Paul later goes on to further construct this difference as "just a nice chat" [line 1380] versus "work[ing] out a survival plan" [line 1382]. This constructs grief as life-threatening and requiring professionals' strategic input, which counter the assumptions held within traditional bereavement counselling in which the client is encouraged to tell their story (Walter, 1999) so as to express their emotion (Anderson, 2001) and "get through" it. Illich (1975) argues that "culture confronts pain, deviance and death by interpreting them; medical civilisation turns them into problems that are solved by their removal (p. 93)".

Paul uses a number of rhetorical devices to achieve specific functions in his talk. Firstly, he uses a concession to preface the decision he has made in taking antidepressants as a treatment for grief, which is achieved by outlining his own reluctance and relaying the psychotherapist's view before presenting the case for

medication. Paul's use of "the hell" [involved in this] and "reached rock bottom" both represent extreme case formulation, which strengthens his construction of grief as intolerable and legitimises the desperation he feels in his grief. His addition of the word "just" [go through it], conveys his scepticism about this approach, which affords him the position of having no choice and at the mercy of professional expertise.

By employing repeated speech when he says "look you're seriously depressed..." Paul strengthens the rationale for medication made by the bereavement counsellor, by using their words rather than his own to convey the sense of an objective 'truth'. This relates to Foucault's conceptualisation of 'power/knowledge', which considers power as being enacted via certain forms of knowledge; particularly those which privilege scientific understanding and 'truth' (Foucault, 1977). Given the concerns Paul relays about taking psychotropic medication, the use of this device could function to relieve the tension he experiences in acting against his previously held wishes about it. Furthermore, it locates the responsibility for managing his mental health with professionals, thus highlighting the power differential this sets up between the two positions (Glaser & Strauss, 1965).

As resourced by scientific discourses, diagnosis and understanding about his emotional experience is encapsulated within a standardised measure of mood, which Paul's use of "did me a questionnaire" is indicative of being 'done to', and serves to emphasise his subject position as passive patient. The weight and significance Paul gives to his 'score' is such that the actual figure itself is not required and the mere presence of 'scoring' is enough to convey the severity of his condition. This highlights the power held within scientifically derived questionnaires as dictating constructions of grief and its management. Comparable to the DSM, this can be considered a technology of power, reinforcing Foucault's principles of surveillance as enacted via the site of the



clinic (Foucault, 1977). Following the account presented in extract 3, Paul later goes on to state:

Extract 6 (FG2): Lines 1384-1385

Paul            and this person had thirty years of experience in bereavement work  
                      (.) and I thought “wow (...) there is a science out there she knows  
                      what she’s talking about”

Here, Paul continues to allude to a hierarchy of expertise within the range of professional helping roles, in which scientific knowledge is considered superior and professional expertise is constructed according to time. Whilst this construction allows Paul to place trust in the medical, drawing on the supremacy of this discourse places Paul as inferior in comparison, which further highlights his passivity in the patient role and reproduces the social practice of seeking professional help in bereavement. As a technology of the self, Paul constitutes himself as a subject; representing an internalised mechanism of power (Foucault, 1988).

Despite the above, other participants spoke of their struggle to access counselling or support groups, which suggested a relative lack of professional support for individuals who are bereaved. The next extract explores alternative accounts, which continue to highlight the professionalisation of grief and illustrate the privilege that is afforded to medically informed ‘psy-knowledge’ within this.

Extract 7 (FG3): Lines 2023-2027

Kate            you have to really dig deep to find groups and support groups and  
                      or get counselling and it’s just almost like (.) it’s not really taken that  
                      seriously, you know, and it’s such a big thing that people have to

face (...) I found that really hard I just feel so on my own and er I'm just trying to find the right support

Kate's account constructs bereavement as unimportant within the context of the professional domain, as illustrated when she states that "it's not...taken that seriously", despite it being such a "big thing people have to face". This is in contrast to Paul's account in extract 3, which via the construction of grief as a mental illness, leads professionals to consider him to be "seriously depressed". This suggests that when the professional conceptualisation of grief sits outside of the context of mental illness, it is considered as inferior in comparison, which produces subject positions for bereaved individuals of unsupported and alone. Furthermore, Kate's use of having to "dig deep" to seek out support communicates the energy that is involved in this task, and the struggle this engenders as a result. Later on in the discussion, Karen also describes being informed she had "slipped through the net" [FG3; line 2089] by a bereavement counselling service, after not hearing back from them for months. Kate's use of "the right support" reinforces the assumption that grief is a condition to be managed professionally, and indicates that different forms of support may be deemed more or less "right".

Having said the above, the next extract demonstrates that the avoidance often associated in response to death within British society (see Valentine, 2006), can be additionally enacted within professional interactions, thus reinforcing the broader assumptions that death cannot be spoken about.

Extract 8 (FG3): Lines 2096 - 2101

Karen            he said "can you think of any reason [laughter in group] why you've not been sleeping?" [more laughter] I really wanted to punch him (.) but actually I sat there and said "I think it's probably because my husband died" and then here's this deadly silence and actually at

that point, I thought “you came to the house you signed the death certificate <Marion: oh no> you are the regular GP, if you aren’t there for me I have no hope at the end of the day”

This extract further illustrates how discourses of medicalisation shape the social practice of going to the GP for medical treatment for the impact of bereavement. Some speakers also made reference to unhelpful interactions with their GP. In her account, Karen adopts repeated speech to recount the interaction between herself and the GP. This not only serves to differentiate their respective positions of doctor and patient (highlighting the power relations within the relationship), but also enables her to inject humour into her story, which is received as such by the rest of the group.

In fact, humour was incorporated frequently into speakers’ accounts within this study, particularly at points when participants were talking about distressing aspects of their experiences, such as this. Typically, this functioned to ‘lighten the mood’, perhaps enabling the conversation to feel more manageable. This is reflective of the so-called ‘black humour’ discourse that is frequently drawn upon in conversations about death within a traditionally British society (Young, 1995). As a consequence of her use of humour, and the subtle mimicry with which she caricatures the GP’s words, Karen is enabled a more empowered position from the sense she gives of feeling patronised at the time.

Avoidance of grief by the GP is constructed through Karen’s use of his “deadly silence”, which is particularly fitting given the context of her appointment. This also conveys a sense of danger or mistrust in the act of silence. The operation of power is enacted via the dynamics of the relationship, as achieved by Karen “want[ing] to punch him”, but instead giving him a polite and honest response.

Karen’s statement “you came to the house you signed the death certificate”, poignantly conveys her subject position of being forgotten by the GP, which

enables subjective feelings of being unimportant. In contrast to the laughter Karen receives as indicated in the first two lines of the extract, Marion's "oh no" highlights the empathic response Karen receives by the group in hearing this. This demonstrates agreement with Kate's comments in the previous extract, and highlights the marginalisation that bereaved individuals can be subject to within society – even by those in a professional role. This is encapsulated by Karen's final statement of the extract, in which "if you aren't there for me" alludes to her disappointment in the medical profession and the subjectivity of hopelessness this affords for her.

Later on in the discussion, Karen returns to this topic, stating "I appreciate GPs are very overworked but (...) in the films [they] would come round to your house and say "here is your little pack" or whatever, but in reality" [lines 2157 – 2159]. This is further suggestive that the control and responsibility for bereavement is located within professional institutions, via the dissemination of formalised guidance, which places the bereaved individual in the subject position of uninformed and as requiring advice.

Within extract 6 as a whole, the GP's role in signing the death certificate signifies the power that is afforded to medical professionals to legitimate death. The powerful contrast between this, and the silence Karen is subject to in response to her reference of death creates a distinction between the professionalised management of the body, and the emotionality that is associated with the mind, as resourced by Cartesian notions of dualism.

### **3.3 Individualism**

Speakers' accounts of grief were often resourced by strong discourses of individualism, which is informed by ideologies of self-sufficiency and self-responsibility (Valentine, 2008), placing value and achievement within the individual (as opposed to the state or collective group). As a consequence,

individual autonomy, independence and self-reliance are constructed as the vehicles through which individuals are able to determine their own lives, in order to achieve their goals. These discourses are tied to powerful assumptions held within a prevailing neoliberalist society, in which the influence of privatisation has extended to the domains of emotionality and behaviour (Barnett, 2005). As a consequence, individuals are encouraged to engage in practices of self-examination, self-care and self-improvement (Rose 1985).

The discursive activity resourced by this discourse will be examined using three key sites that took place within conversations: 'an individual experience'; 'a personal responsibility'; and 'sharing grief (resisting privatisation)'. Since it is not possible to capture every example that arose within the accounts, only the most pertinent will be presented, in order to demonstrate the subjectivities and social practices these constructions enabled.

### 3.3.1 An Individual Experience

#### 3.3.1.1 *The uniqueness of grief*

The assumption that grief exists as an individual experience is well documented within the bereavement literature (see Breen & Connor, 2007). This was demonstrated frequently and in numerous ways within the accounts that took place in the group discussions. In common with medicalisation discourses, individualism locates grief within the individual and while the two often overlapped and co-existed in people's talk about grief, drawing on individualist discourses enabled speakers to achieve different outcomes in their talk.

Extract 9 (FG2): Lines 2002 - 2011

Dave (FG2) I think that's dawned on me in the past couple of weeks but, yeah it is (.) everyone works so differently in terms of how they react to it (...) that it's – I don't think you can (.) um have a (.) you don't

find a method of helping – “right this is how we help people (.) who’ve lost a partner”, you know, well you say “well you can’t do that because we’re all so different in the way we react to things...”

In this extract Dave constructs grief as being unique to the individual, which he considers as reflecting a new direction within his thinking. By drawing on an individualist discourse, Dave is able to counter the assumptions of prescriptivity and universality implicit in biomedical and psychiatric frameworks and question the legitimacy of standardised approaches to bereavement care. Furthermore, his use of the word “find” [a method of helping] directly contrasts with Christine’s account presented in extract 1, who constructed grief as an objective ‘truth’ the pursuit of science can uncover.

As previously stated, research has proposed that by imposing normative expectations about grief, individuals may feel pathologised or invalidated if their bereavement experiences diverge from what is considered ‘normal’ grief (Wortman & Silver, 2001). Through his rejection of these assumptions, Dave is legitimised in any deviation he experiences within his bereavement and is able to resist the potential corresponding subjectivity of failure.

When Dave states “that’s dawned on me” he conveys the sense of coming to an enlightened realisation through which he is positioned as having greater authority over his own and other people’s grief experiences. Despite the assumptions within his point, his use of “we” serves to unite the group, perhaps suggesting that bereavement, as a broad concept remains a shared experience.

#### 3.3.1.2 *The uniqueness of cancer*

Many of the speakers constructed grief as being inherently influenced by their experience of cancer, which corresponds with existing cancer bereavement literature (e.g. Fasse. et al., 2014). The following extract demonstrates how

participants constructed the link between cancer and their subsequent grief response.

Extract 10 (FG3): Lines 1372 - 1375

Gill            every cancer's different so it – every cancer's different <yeah> and everyone's experience is different <hmm> so, you know, there's no cure at all out there is there [long pause] so everybody's experience of grief is different too <hmm>

Gill's repetition in the first line of the extract, together with the emphasis she places on the word "every" serves to stress the point she is making, which is to suggest that no unifying conclusions can be drawn about the illness, and that one individual's experience of cancer will necessarily differ from another. Gill incorporates the rhetorical device of extreme case formulation throughout the account, which further strengthens her arguments and builds to her construction that as a consequence, grief is an individualised experience as well. The individuality of grief is additionally linked with Gill's question "there's no cure at all out there", which constructs the uncertainty involved in cancer described in the existing literature (e.g. Olson, 2014) and as resourced by medicalised discourses, enables her to locate the responsibility for death in the failure of medical knowledge and technology. Valentine's (2008) research into bereavement narratives highlights how the institutionalisation of dying leads to the assumption that dying is as a condition to be treated, which enables and privileges the production of biomedical research as an institutional practice.

Gill's account characterises many of the conversations that were held relating to the specificity of cancer bereavement via constructions of its unpredictable trajectory and the impact this had on grief. These constructions engender the subject position of powerlessness, rendering participants at the mercy of the illness.

### 3.3.2 Personal Responsibility

The assumptions of individualism outlined above were evident in how people talked about grief as a personal task that they were required to undertake alone. In order to demonstrate this, I have structured the section in accordance with four key social practices that this discourse enabled: anticipation of death; personal burden; privatisation of grief; and protecting others.

#### *3.3.2.1 Anticipation of death*

As discussed in chapter one, the term ‘anticipatory grief’ refers to the development of grief within individuals in response to the deterioration in health of a terminally ill patient, which extends beyond their death and influences subsequent bereavement (Rando, 1986). This construct is well attended to within the literature and frequently associated with experiences of cancer bereavement. Participants who took part in this research were also found to construct their grief in accordance with this concept, which further supports the view that this type of bereavement affords individuals with specific subjective experiences.

Extract 11 (FG3): Lines 56 - 61

Gill            he had a seizure and um that was the beginning of the end and it took us two two years and one week and I had quite a lot of people say to me “you’ll need to grieve as you go along” but it’s it was brain cancer and it’s easy to grieve as you go along because you lose bits of them as you go along <hmms> and there’s no way um there’s no way that they’re gonna come back from it they’re just melting in front of you

In this extract, Gill constructs the initiation of grief in accordance with her partner’s physical deterioration, drawing attention to the dehumanised nature of terminal illness as reflected by her description of “lose[ing] bits of them” and her



use of the word “melting”. As a consequence, loss is also constructed in terms of her husband’s identity and personhood.

Gill relates the commencement of her grief with the advice provided by other people that this was a necessary response in the management of cancer. The use of repeated speech emphasises that this was other people’s ‘advice’, which conveys the prescriptivity and universality as available discourses that are drawn upon within sense-making about cancer in society. This reflects expectations for social practices that manifest as self-regulation within the individual, therefore representing a technology of the self.

Although in this extract Gill refers to her husband’s seizure as signifying “the beginning of the end”, many of the other participants with the three groups made reference to the formal diagnosis of cancer as the initiating point of their grief, which, for some took precedence over the presence of physical manifestations of the disease. This highlights the power of medical diagnosis, as delivered by medical professionals (‘done to’), which renders both patients and caregivers as powerless and shapes the social practices of grieving as a response – therefore constituting a technology of power.

Gill’s use of “no way” conveys her certainty of death, which enables her grief to take place, in accordance with notions of anticipatory grief. This is in contrast to other accounts that refer to the uncertainty and unpredictability of the illness as having an alternative impact on grief, as the next extract illustrates:

Extract 12 (FG3): Lines 75 - 78

Karen            the whole thing just hit us like a train <hmm> and so ours is a bit  
different really <hmms> because one it just hit us and – and  
because I was still down the sort of “don’t worry you’re going to get

better” route I actually feel terrible now because I think I should’ve been having these meaningful discussions

Karen uses the phrase “hit us like a train” twice in this extract, and it features a third time earlier on in her account. This emphasises the extent of the shock that she and her husband had experienced in response to the terminal nature of his cancer and subsequent deterioration towards death. Her use of “us” and “ours” conveys the continuation of the relationship following her husband’s death, reflecting the discourse of continuing bonds (Klass et al., 1996). In contrast, she switches to “I”, which she stresses, to locate responsibility for holding hope [“going down the ‘don’t worry you’re going to get better’ route”] within herself. This is resourced by discourses of hope that are influential within cancer and palliative care contexts (Draper, 2009). In Karen’s account, hope is constructed here as a mistake for which she [now] feels “terrible”, due to it preventing her from being able to initiate “these meaningful discussions”. Here, “these” highlights the social expectation to have particular end of life conversations, which is indicative of discourses of ‘severing ties’ and ‘saying goodbye’, inherent in traditional stage models of grief. This demonstrates how conflicting discourses co-resourced participants’ accounts about death and dying, and the feelings of guilt that can be experienced as a result. The word “should’ve” further implies the presence of obligation in this social practice around dying.

Other speakers described a similar desire to have been able to exchange such ‘parting words’ with their partners. The nature of these kinds of conversations was alluded to by Andrew (FG1), for whom saying “it’s ok to go now” and giving “permission to die” represented “the sort of things you’re s’posed to say” [lines 720-722].

### 3.3.2.2

#### *A personal burden*

Extract 13 (FG2): Lines 226 - 248

- Paul            because nobody else can carry it <hmm> um my wife, who died always used to say throughout her life, she knew she'd have to die alone, it worried her but you die alone whatever she thought it meant you grow up and you die alone (.) but my goodness it's hit me since you grieve alone because nobody else can get inside my head (.) know what it's like and take that burden away (.) but as I say the the closest – in my case I'm lucky I have some family – children (.) and they're missing the same person they're missing exactly the same person (...) but not the same relationship/  
Aanya        /they may, yeah certainly, they will have a different feeling/  
Paul            yeah (.) and they all have their partners (...) so they're not stranded in the same way

Alongside Paul's use of the word 'burden', this extract illustrates grief as being a heavy weight, the construction of which was shared by other speakers. For example, in speaking about seeing more of his late wife's friends as a way to manage grief, Andrew (FG1) questions "a perception that whether I'm a bit of a charity case um and you know also putting too much onto them" (lines 2246 - 2247).

By drawing on individualism discourses, Paul positions himself as alone in his grief, which constructs grief as a personal burden due to its location within his head. The stress he gives to the word 'nobody' emphasises this sense of aloneness. Similarly, death (which Paul compares to grief) is constructed as an individual process which is further resourced by Cartesian 'mind/body dualism', through which the materiality of death ultimately renders the body alone. This comparison enables Paul to construct grief metaphorically as residing within the material brain of the individual, thus rendering support by others as redundant. In

fact, 'support' here is constructed as removal of the burden, which Paul describes using a metaphor that is suggestive of an intrusive medical procedure, which produces the subject position of being a passive patient.

In the final part of the extract, via co-construction, Paul and Aanya differentiate spousal from other forms of bereavement. Distinguishing between "the same person" but "not the same relationship" not only renders individuals as alone in grief, but the agreement that is achieved through their interaction serves to suggest this is a shared experience within the group.

### 3.3.2.3 *Privatisation of grief*

A dominant discursive site within participants' accounts constructed grief as an experience that should be kept hidden from other people, ensuring it remained a private experience within the individual. Individualism discourses create expectations of the self and shape self-regulating practices that dictate the self-management of grief (Small & Hockey, 2001). In particular, participants' talk often constructed the privatisation of grief through the social practice of crying, which represents a visible marker of emotional distress that is displayed in accordance with particular social rules "that attempt to govern who when where how long and for whom people should grieve" Doka (1989 p. 4).

Extract 14 (FG3): Lines 977-985

Angela        I was fine if people just treated me normally as if I was at work um  
                 "sorry for your loss" um but not [puts on voice] "oh I'm really sorry,  
                 are you ok?" <hmm> it was – as soon as somebody gave me  
                 sympathy (.) was when I fell apart <hmm> and I said "just don't be  
                 nice to me <hmm> I'm Ang, just talk to me normally (...) and I still  
                 have a big problem with people coming up to me and and and  
                 giving me a hug and and and being the nicey nicey part I just can't

– I just personally can't deal with that bit, it just makes me (.) bawl  
<hmm> (.) and I get very fed up crying

In this extract, Angela's account illustrates the normative social practices of being "fine" as opposed to "when I fell apart" in determining the construction of grief as a private experience within the individual. The contrast between Angela's constructions of falling apart as an expression of grief versus being "fine" produces the subject position of vulnerable. From a Foucauldian perspective, the emotional self is shaped and reshaped via discourses about emotions including 'feeling rules' as a continuous project of subjectivity (Lupton, 1998; Hochschild, 1979).

Foucault (1977) proposes that technologies of normalisation occur through subtle processes of self-surveillance that individuals engage with in accordance with social expectations. The power of the normalisation is emphasised by Angela's repeated use of the word "normally" which is suggestive of her self-policing and self-monitoring with regards to the expression of her grief. Harris (2009) suggests that overt emotional expression is often stigmatized, leaving bereaved individuals to feel embarrassed about their loss of control in front of others.

In addition to drawing on individualism discourses to construct grief as a private experience, speakers drew on patriarchal discourses, which reflected gender norms relating to stoicism, constructing the expression of grief as taking different forms according to gender. This is demonstrated by the next extract.

Extract 15 (FG3): Lines 1043 - 1052

Neela            (...) they just wanted me to behave in a certain way to lean on them  
                      (.) and just fall apart and then they'd say "there there" put me back  
                      together again (.) and because – I was trying to be strong and I'm  
                      not the crying type, I mean, worst situation and I just can't make

myself cry (...) you know I'd try to say to them "look perhaps I've got a male kind of personality where men can feel things very deeply, but they don't go around and cry their eyes out on <hmm> their friends shoulders (...) so why are you expecting me to - so just think of me like that if somehow you feel that I'm blocking it out I can't function any other way"

Marion        it's so it's so deep that it's impossible to to /show (.) in that sense/

Neela         /and what will they do anyway I mean if, you know, to make you feel better

Like Angela in the previous extract, Neela refers to behaving "in a certain way" as to "just fall apart", which constructs the emotional expression of grief as losing control. This relates to assumptions that exist about bereavement, in which the absence of tears following death can be perceived by others as denial, and the occurrence of profuse weeping within a particular time frame after death can be seen in contrast as 'letting it out' (Anderson, 2001). By employing repeated speech when she says "there there", Neela indicates a sense that she feels infantilised by her friends' responses, which position her as vulnerable or weak as well as highlighting her resistance to revealing her grief.

Neela goes on to construct grief according to the dominant social norms about emotionality and gender, and the respective social practices that males and females are afforded. These constructions are further resourced by discourses of patriarchy, in which the primacy of a normatively masculine response to death produces expectations of stoicism, and the denial of overt emotionality across genders (Harris, 2009), via emotional self-regulation that take place within the individual. This was additionally emphasised elsewhere by Scott (FG3) when he states that "blokes don't generally talk about their feelings so I think they'd feel even more awkward (.) probably more awkward than me" (lines 968-969). Neela's account allows her to resist the vulnerability in being bereaved that was

constructed in Angela's account in extract 9 allowing Neela to be "strong", as she refers to in the extract.

The two final comments included in the extract demonstrate the co-construction that takes place between speakers in the group. In response to Neela, Marion's construction of grief as being "so deep that it's impossible to show" builds on the implications within Neela's talk, further revealing the powerful assumptions that "deep" feelings cannot be shared. The use of the word "impossible" suggests there is little choice in this decision. Instead it highlights the powerless position she feels placed in by the expectation to align with such assumptions. This appears to be a shared position between the two speakers, as indicated by Neela's last comment.

#### 3.3.2.4 *Protecting others*

Participants' accounts often spoke about grief as something that other people needed to be protected from. This particularly appeared to influence the expression of grief within the family system. According to Walter (1999), emotional volatility can represent a powerful challenge to the status quo, whether this is within the family or the state. This appeared to be evidenced a number of times by different speakers by statements such as "I'd find it easier to cry and fuss in front of a stranger than I would in front of my family" [Neela: FG3; Line 1435].

Extract 16 (FG1): Lines 377 - 392

Lucy	and two weeks later he died, so it all happened very quickly and my family (.) like (.) literally just couldn't bear it basically and they didn't, you know, they just couldn't you know my mum, I think it just brought up a lot of feelings for my parents about the loss of <hmm> their son um and so I just had to kind of sort of (.) cut them off in a way, you know, and (...) you (...) talk about people asking how you
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are – that they couldn't ask me how I was because they were so afraid of the answer (...) on the other hand I had a very very supportive group of friends who (...) basically [Lucy laughs] organised a rota um where people - my friends –were kind of coming into hospital and they were there from the moment I was there until I left and then they'd take me back to their apartments and that went on for like, two months

In this extract, Lucy constructs grief as unbearable, which she connects to the speed with which her partner had died following his admission to hospital. By deciding upon the word 'couldn't' instead of 'didn't', Lucy conveys a sense that grief *is* unbearable, which reveals the lack of agency and powerlessness that is felt in response to death and the grief that follows it. By constructing grief in this way, she is able to absolve her parents from their inability to “bear” her grief, which may serve to allow her to avoid feeling angry or blaming of them for this.

Lucy constructs grief as existing in isolation and as located within the individual as an experience that cannot be shared between family members. By drawing on her parent's previous loss of a son, she highlights the reciprocity involved in this, preventing either party from being able to share their grief. As a technology of the self, the need to “cut them off” is reflective of a self-regulatory practice, which is reinforced by constructions that grief is something to be feared. As a result, this prevents open communication about it, producing subject positions of being a protector and as rejecting of others, but at the same time renders Lucy powerless as a consequence of being silenced by the expectations that are held within society.

Despite the comparison Lucy makes between her family and friendships, the description she gives of her friends using a “rota” in their support for her is further suggestive that grief is considered a difficult task for others to manage, therefore requiring the input of logic and organisation. This is reflective of the dualism



between rationality and emotionality as encompassed within the enlightenment (Small, 2001). However, the use of “rota” is also resourced by discourses of productivity, through which the management of grief is likened to work. This engenders subject positions of having a duty/job to do in the face of someone else’s grief.

### 3.3.3 Sharing Grief: Resisting Privatisation

This section explores the subjugated discourses that were evident in some of the participants’ talk, which served to resist the dominant expectations of keeping grief as private and the need to protect other people in society from it. This has been structured into three key sites as a demonstration of this: ‘bereavement as a shared experience’; ‘sharing enables connection’; and ‘experts by experience’

#### 3.3.3.1 *Bereavement as a shared experience*

A number of the speakers contrasted their experiences of feeling silenced and unable to express grief with other people, with a relative openness to talking amongst others who were also bereaved, as the following extracts demonstrate.

Extract 17 (FG3): Lines 1378 – 1390

- Neela            ‘cause [the current service] is about the only place where I can actually talk about it easily (.) even to my friends who’ve done – been the best friends around and been there I don’t really open up and talk to them (.) ‘cause I know they can’t
- Marion           <I don’t, not to anybody>
- Neela            but I can here, somehow
- Marion           yeah, this is the only, yeah it’s the only time that I ever do
- Neela            and I was avoiding coming to the support groups because I said to the counsellor when she recommended that I try them out I said “I dunno I’m not that type, I’m not the type”

This extract demonstrates how agreement and interaction within the discussions served to co-construct grief as being a topic that it is possible to share with others who are bereaved. Additionally, implicit in these accounts is the value in being able to “actually talk”, despite not “opening up” within other sources of support. As a consequence, these accounts reinforce the expectation for individuals to keep grief private and protect other people, as outlined in the previous sections. However, a clear distinction is made between the management of grief within relationships in existing social networks (which is constructed as being problematised by both speakers in the extract), and alternative methods for managing bereavement such as attending a bereavement support group. Interestingly, both speakers use “here” and “this”, referring to the research focus group, which suggests a similarity between the two and the benefit of shared experience across contexts.

Neela’s use of the words “talk about it easily” and “but I can here somehow”, suggest a certain degree of liberation in shared experience, in contrast to the restriction Neela is usually subject to. This enables a position of empowerment and resistance from the self-surveillance practices she engages with in order to monitor her expression of grief. Neela’s statement that the support group she attends is “about the only place” she can talk about grief highlights an absence of alternative forums in which grief can be shared. This comment is made in the context of her attendance to counselling, which suggests its limitations in enabling this.

Mutual self-help groups have been defined as ‘communities of pain’ (Riches & Dawson, 1996), representing a “counter-culture” (Small & Hockey, 2001, p. 114), in which the management of grief becomes a shared goal. Further, by operating in opposition to the dominant modernist assumptions of obtaining resolution and closure, individuals who attend such groups can be afforded a certain ‘release’ from traditional expectations (Walter, 1999).

Neela employs the rhetorical device of stake inoculation by incorporating her previous scepticism about support groups as indicated by her repetition of being “not the type” of person who attends a support group. Later on in her account, Neela states that “for me grief is private” [line 1391]. Rhetorically, this could be seen to build her argument for sharing grief, which further enables her to resist the powerful assumptions of privatisation.

### 3.3.3.2 *Sharing enables connection*

Extract 18 (FG1): Lines 2141 - 2161

Lucy            by being open about it and being relaxed about it and talking about what happened um I’ve ended up meeting some amazing people, (...) I certainly experienced that with my parents growing up like, you know, very afraid of death and (...) will keep it kind of locked inside and actually (...) the more open you are about it the more you can kind of share experiences and that’s a much more – for me anyway, that’s been a much more positive way of (...) dealing with the grief (...) it’s through (...) connecting with people.

Lucy’s account demonstrates a resistance to the dominant discourses about grief necessarily being a private experience that is limited to the individual. She constructs such internalised grieving as problematic by drawing on societal discourses surrounding death (which enable it to be a phenomenon to be feared) and alluding to the social practices these produce, as “keep[ing] it locked inside”. As a metaphor, this suggests that private grieving is akin to imprisonment, engendering subjectivities of oppression within the individual. By adopting an alternative position of “being relaxed” and “talking about what happened”, Lucy is afforded liberation from the fear perpetuating the so-called ‘death-denial’ (Valentine, 2006) and greater empowerment within her experience of grief.

This constructs an alternative method of management for grief in comparison with others that are resourced by medicalisation and assumptions of self-regulation, both of which are located within the individual. Instead, Lucy constructs the sharing of grief, which enables her social privileges in terms of “meeting new people” and “connecting with people”. This relates to previous suggestions that bereaved individuals become marginalised within society (Reynolds, 2002; Harris, 2009). Through the active expression of her grief within the wider public domain, Lucy is able to resist such marginalisation and the corresponding social isolation this has been found to engender (e.g. Stroebe, Stroebe & Hansson, 1993).

#### 3.3.3.3 *Experts by experience*

Extract 19 (FG1): Lines 319 - 327

Keith            what I found was, when people said “oh how are you?” you know I mean part of you wants to say [laughter in group] “well how d’you think I am? <yes> My partner d-you know” [Keith laughs] <yes yes> but I took the opportunity often to say “well (.) is that a serious question? (.) ‘cause if it is, you know, then we can talk about that” and I took the opportunity to actually explain how I felt, which I found helpful <hmm> and I think it helps other people put their reticence to talk about it down as well

Lines 2110 - 2118

Keith            so we can uniquely because of our experience help other people talk about this (...) ‘cause (.) if they’re not going through it like we are at the moment they’ve been through it before or they’re gonna go through it at some point

These extracts demonstrate the presence of an alternative subject position that is made available via Keith’s questioning of the assumptions that are held within the

question “how are you?” in the context of grief. As earlier extracts have demonstrated, dominant discourses about grief construct it as something to be feared and kept hidden, the practice of which is signified by the response “I’m fine”. As a consequence, these discourses produce positions of silenced and vulnerable. In contrast, Keith is able to confront the expectations for normalised social practices within social interaction and communication around grief. This affords him the authoritative position of ‘expert by experience’, and as an educator, as opposed to the position of powerless. Rhetorically, Keith’s use of repeated speech to illustrate the conversations he is speaking about serves to resist the silencing, by providing himself with agency, as further highlighted through his use of humour in that part of the account.

This account is achieved by drawing on discourses about bereavement being an inevitable aspect of human life, which achieves qualitatively different consequences to the assumptions of universality held within medicalised discourses. In direct opposition to the powerlessness associated with positions of ‘abnormal’, ‘defective’, and ‘mentally ill’, and in addition to the vulnerability positioning seen in the privatising grief section, Keith’s use of the words ‘unique’ and ‘opportunity’ grant griever a level of expertise and authority over others in society who are yet to experience death. This perhaps relates to what Turner (1974) defines as the “power of the weak” (p.234); that despite the broader disruption this causes within their lives, those individuals positioned as marginalised within society can be afforded sites of unforeseen empowerment, as a consequence of their pain.

Keith’s perspective affords him to be transparent about how he is feeling and empowers him to feel able to encourage others to speak about death, rather than avoiding it or keeping this hidden. As a consequence of this positioning, channels of communication are opened up allowing conversations about grief to take place and constructing grief as a phenomenon that can be shared. At the discursive level, Keith uses ‘us’ and ‘we’ which functions to unite the group in

accordance with their shared experiences, and places him in an authoritative position within the group.

### 3.4 Productivity and Purpose

A common site of discursive activity that was observed within speakers' accounts was resourced by economic discourses that are shaped by powerful capitalist structures within society. Fundamentally, value is placed on sustaining economic growth via consumerism, productivity and competition (Harris, 2009). Throughout the discussions, participants constructed grief as the absence of productivity as illustrated by statements such as "having a lot to do but not doing it"; "it's as if I'm paralyzed"; "incapacitated". The ways in which talk was resourced by discourses of economy and productivity will be described using three key constructions: 'keeping busy'; 'working helps'; and 'marriage as purpose', as representatives of the most powerful and pertinent across the data.

#### 3.4.1 'Keeping Busy'

Extract 20 (FG3): Lines 1629 – 1641

Angela I was like a mad woman (.) trying to organise the funeral and everything 'cause (...) I just constantly thought that if I had something to focus on (...) I had had to have a goal somewhere along the line and that was – and I still do it even now and I'm eight months along that I'm still "right ok well I planned for this little chart little do" and and everything I do gets put in a box or on a list or in a – and I just sometimes think to myself "you just need to throw it away and just be" (.) but I can't

Philippa <it's too scary>

Angela I can't 'cause it's a bit like a security blanket <hmm>

The accounts presented within this extract are representative of various conversations that took place in the study, in which grief was constructed as something to be avoided via distraction. This was resourced by notions about the value of keeping busy. Throughout her account, Angela uses terms typically associated with economic and business contexts, such as ‘goal’ and ‘plan’, which enables her to feel productive and as progressing towards an achievement.

As Phillipa’s contribution highlights, grief in the absence of a busy routine is constructed as scary, following which Angela’s reference to a ‘security blanket’ produces the subject position within society of being vulnerable. Reflected within capitalist structures is Foucault’s concept of ‘regime of truth’ (Foucault, 1977), in which the operation of power is reproduced by the self-regulatory practices that adhere to the capitalist regime. This includes the expectation to contribute to consumerism and economic output and practices that are further informed by discourses of individualism. The inherent power that exists within this regime is particularly notable given Angela’s comment alluding to her sense of the need to “just be” with grief, which carries a potential threat to the capitalist structure (Harris, 2009).

#### 3.4.2 Working Helps

Work was frequently constructed as a solution to the ‘problem’ of grief, with many accounts constructing the return to employment as a productive way in which grief could be managed. In contrast, the absence of work enabled problematised constructions of grief as the following extract illustrates.

Extract 21 (FG2): Lines 436 - 443

Paul            is so terrifying (...) that I have to go back to filling the diary (.) but actually it’s exhausting – I wish I had a PA (...) to fill the diary – to fill my day with social events and it’s my own fault, I’m already

retired (.) perhaps I should go back to work – but I haven't got – I  
can't find the energy (.) to go back to work

In this extract, grief becomes problematised in the absence of being able to use work as a distraction from it. Having to fill his diary with social events due to his retired status highlights the hierarchy of power implicit within these respective activities. In stating that “I wish I had a PA” to fill his day (constructed as “terrifying”), Paul conveys an emptiness to his life, now that he is both retired and bereaved. He additionally locates the responsibility for this in an employment-related role that places him in a passive position.

Retirement prevents individuals from being able to contribute to the economic work-force, rendering them of little use in wider society. Foucault (1977) used his conceptualisation of ‘docile bodies’ to propose that as a result of the exercise of disciplinary power, “[individuals] may be subjected, used, transformed, and improved” (p.136), which illustrates how individuals are subjected to institutional regulation. In the context of capitalism, this process engenders value in those individuals who can contribute to the economic workforce, affording them purpose and meaning in life as a consequence. Paul’s comment that “it’s my own fault” suggests that he locates responsibility for the extent of his grief within himself for removing himself from the domains of work and productivity. This could be considered a technology of the self, whereby his self-blame is representative of Foucault’s notion of self-surveillance. This account therefore powerfully illustrates the double marginalisation that retired individuals who are bereaved are subjected to.

#### 3.4.3 Marriage as Purpose

A key discursive site within participants’ accounts was located within the institution of marriage, as a practice that resourced their constructions about grief and loss. Specifically, marriage was constructed as a vocation, through which speakers were able to feel productive and gain a sense of meaning in their lives.



As a consequence, following the death of a partner, grief was constructed as taking away the means to be productive, rendering the bereaved individual as purposeless and serving to further problematise grief.

Extract 22 (FG2): Lines 1237 - 1252

Paul            I haven't yet found a new thing to live for (.) I can dream of one day being useful to other people again um I am actually useful as a babysitter for my grandchildren so I'm quite lucky there and I can cook for them that sort of thing, but I've lost a role in (.) society (...) it's also had the opposite effect in that actually I did do eighteen months of solid cancer care and (.) actually I probably did it pretty bloody well (...) sometimes I think "well I was quite a good husband actually", I actually did what had to be done and I didn't – you know, that – so I haven't lost confidence on that level, but it's the losing of confidence in what to do next

In this extract, Paul's construction of grief as the absence of purpose is strongly influenced by the assumptions inherent within a capitalist regime, as outlined in the previous section. His inability to find a "new thing to live for" locates his sense of purpose within the spousal relationship, through which his role as husband enables him to feel useful to other people. In contrast, constructing the impact of grief in this way enables the subject position of being useless, despite the relative use he achieves within his role as a grandfather. This is implied as being somewhat limited, given his statement that he has "lost a role in society". Through his talk, Paul is alluding to the power that exists within the spousal relationship, as resourced by the institution of marriage, thus representing a discursive practice (Foucault, 1972). As a consequence of the death of his wife, he is rendered powerless within society due to the 'widower' status he is now afforded.

As was the case for the majority of speakers in the study, the extract highlights the additional role of caregiver Paul was required to undertake, which represents another site through which purpose can be achieved. In his final statement of the extract, Paul states that he has “lost confidence in what to do next”, which constructs loss in terms of the roles he no longer has, emphasising his need to find a new sense of purpose.

#### 3.4.3.1 *Female constructions of achievement and responsibility*

As a consequence of their bereavement, many of the female speakers in the groups constructed grief in the context of the new responsibilities they had been required to take on, following the death of their husbands. For some of these participants this responsibility equated directly with grief and contributed to their sense of burden. For others, however, loss was constructed as enabling subjectivities of achievement and independence, which was influenced by normative assumptions about the female role.

Extract 23 (FG3): Lines 1925 - 1979

- Marion        you are feeling so responsible and then when you do actually achieve something (.) then it almost pulls you – sometimes it takes you forward but sometimes it takes you back again ‘cause you sort of feel guilty that you actually managed to do it without that person there (...)
- Karen        <yeah>
- Philippa     yeah
- [29 lines missing]
- Marion        I’d never of dreamt to be able to (...) take responsibility again for such a huge thing [replacing the windows] (...) I thought “oh he’d be really proud of me now”

Gill                    But (.) but I know what you mean because you don't want that pride  
                             (...) you want them to be there to do it [Gill laughs] (...) I'd rather –  
                             I'd rather of cooked the Sunday lunch and just got on with things

In this extract, Marion is constructing loss in the context of achievement of her additional responsibilities as a woman who has lost her husband. Achievement and independence are typically associated with the assumptions implicit within neoliberalism, however, due to the loss of her partner, instead she refers to feelings of guilt for having accomplished these alone. This is evident when she contrasts being taken forward with being taken back. “It almost pulls you” conveys a sense of passivity in this, which implies that she feels out of control.

Implicit in her statement “that you actually managed to do it” is the assumption that certain tasks are not usually achievable by women. These assumptions are shaped by discourses of patriarchy. To contextualise Marion's account, she was speaking in a group comprising seven other females and one male. Her use of “you” (instead of “I”) throughout this extract therefore, served to unite many of the women through their shared experience of this. The agreement that is conveyed by the response other women give to this highlights the co-construction that took place within this site of conversation. This is further implied in the second half of the extract, in which Marion states that “she had never dreamed of” successfully completing tasks that had previously been left to her husband. Demonstrating success as a woman who is independent from her male partner typically goes against the expectations held within traditional discourses about a woman's role within a marriage, which position women as inferior to and dependent upon their husbands (Heath & Ciscel, 1988). Gill's statement that “I'd rather of just cooked the Sunday meal and got on with things” highlights how productivity from a female perspective is often achieved via the undertaking of tasks that are stereotypically associated with the female role, which the death of a husband can disrupt.

This section highlights how competing discourses of individualism, ensuring productivity and the ideologies contained within the institute of traditional marriage, create tensions that influence how women negotiate the death of a spouse.

#### 3.4.3.2 *To have (or not to have) a new relationship following loss*

Within the context of marriage and the death of a spouse, participants' accounts raised the topic of new romantic relationships, alluding to expectations within society for this to take place. This is a dilemma that has been reported in previous research into spousal bereavement (e.g. Lowe & McClement, 2010). The following section explores how the influence of multiple discourses impacted on speakers' constructions of grief and loss, resulting in opposing discursive practices through the illustration of two extracts.

Extract 24 (FG1): Lines 2696 - 2710

Mary            I find people will like keep saying to me, friends 'n' that "oh you need to get back out there, it's time you got yourself somebody else" (...) and I said "look, you know I was twenty when I got married (...) he's my whole life" (...) um I would never bring someone else into my home (.) it was his home you know, um, I'm just not interested (...) I don't particularly need a man, you know I'm quite independent anyway, I've always worked er and I certainly don't need anybody for money or anything like that

Mary's account is resourced by multiple dominant discourses about marriage and discursive practices of grief as a woman, which create tensions within her talk. Her emphasis on the word 'never' conveys her sense of disloyalty at the prospect of a new relationship, which is resourced by traditional marriage discourses, and the expectations of commitment that are held within them. Her use of repeated speech here enables Mary to take an authoritative position, which serves to

reproduce the power held within the institution of marriage, constituting a technology of the self.

Mary uses the present tense when she refers to her husband ['he's'], which constructs her loss within the continuation of her relationship, and counters dominant assumptions about the finality of death. Whilst this may reflect more recent alternative discourses of 'continuing bonds' (Klass et al., 1996), which emphasise the importance of maintaining connection with the deceased, the historical patriarchal construction of 'widows' as grieving indefinitely, has served to prevent women from engaging in new relationships (Davidson, 2001).

As a consequence of her subject position of loyal wife, Mary is able to reject the expectations that she is subjected to, regarding the need to "get back out there" and "time you got somebody else". While these statements draw on dominant discourses that construct grief as time-limited, they are also resourced by powerful ideologies contained within the institutions of marriage and the family, which promote the social practice of being in a couple.

The latter half of the extract further illustrates how Mary negotiates the tension created by the multiple and competing discourses made available to her. By drawing on individualist and economic discourses when she constructs herself as an independent worker, she is enabled the subject position of being autonomous, which prevents her from feeling lonely, or alone in her bereavement.

Mary's account illustrates how the co-existence of marriage, patriarchy and individualism discourses enable certain subjectivities and social practices according to gender. In contrast, the next extract illustrates the difference with which Keith constructs new relationships in the context of bereavement.

Extract 25 (FG1): Lines 2791 - 2804

Keith            if you say it's not that it can't be that, that was that <hmm> but this can still be this (...) it can and it can still be valuable and happy (...) there can be a point in which you're ready (...) and to give yourself the freedom to live is a very important thing whatever that means to you, you know without any kind of obligation one way or the other but I'm happy that I'm having another relationship and I and I don't feel in the least that it's (.) a betrayal (.)

In contrast to Mary, the presence of a new relationship following the loss of a spouse is constructed by Keith as “the freedom to live” and the absence of “obligation”. When he states, “whatever that means to you”, Keith is drawing on discourses of individualism, which signifies personal choice and locates the decision to find a new relationship within the individual, as opposed to an external expectation within society. The emphasis on the word ‘live’ suggests that being prevented from undertaking a new relationship is akin to death, which enables him to feel “happy” developing a new relationship despite his bereavement, and allows him to resist feeling that he has betrayed his deceased wife.

This concludes the analysis and discussion chapter. The findings will be summarised and discussed further in the context of the literature within the next chapter. This will be followed by critical evaluation of the research and an overview of the potential implications it has for clinical practice in the field of bereavement.

## **4. FURTHER DISCUSSION, EVALUATION AND IMPLICATIONS**

The final chapter will revisit the intended aims of the research and summarise the study's key findings with reference to the context of the existing literature. The study will then be critically evaluated and its implications for clinical psychology, bereavement intervention and future research discussed.

### **4.1 Revisiting the Aims of the Research**

The aims of the current study were to examine how people whose spouse or partner had died from cancer constructed grief and loss with one another during conversations held in a focus group. Furthermore, the research aimed to identify the broader discourses informing these constructions, and the subject positions that may be taken up or resisted as a consequence. As previously highlighted, the rationale for this research comes from the notable minority of discourse analytic literature within the field of grief and bereavement. This approach enables exploration of the wider socio-cultural context surrounding the phenomena, and the social practices that are enacted as a result. By taking a Foucauldian approach to discourse analysis, I hoped to examine how the operation of power is enacted within the discursive field and the broader influences informing conversations. These aims were addressed within the previous chapter by presenting three over-arching discursive 'sites' that were identified as resourcing speakers' constructions and the availability of certain subject positions within the accounts. These were 'Medicalisation of grief'; 'Individualism' and 'Productivity and purpose', each of which will now be revisited in the context of the existing literature.

#### 4.1.1 Medicalisation of Grief

The first discursive 'site' was 'Medicalisation of grief', in which participants constructed grief within a biomedical framework and in accordance with medical symptoms and disorders. This finding provides further illustration of the dominance of medical discourses, which, in response to the increasing shift to medical and diagnostic conceptualisations within Western society (Kleinman, 2012) is an indication of how readily professional knowledge permeates lay understanding and sense-making. This construction frequently placed individuals in the inferior position of a patient, which afford subjectivities of 'abnormal' and 'disordered' as a result. This is in line with Valentine (2006), who suggests that a psychiatric conceptualisation of grief may reframe distress as pathological and subsequently requiring treatment. However, the same biomedical resource appeared to legitimise grief for some speakers, serving as a helpful explanation for their experiences and producing the practice of seeking treatment in an attempt to 'recover' from grief. The dilemma in whether or not to take medication for their 'symptoms' of bereavement was an additional feature within the discussions, reflecting existing claims that grief is being increasingly managed with psychotropic medication (e.g. Guldin et. al., 2013). The finding that medical treatment for grief was privileged over other forms of professional input was interesting, with some participants constructing diagnostic approaches to bereavement support as being more useful than those from other professional disciplines. This finding goes beyond existing literature to illustrate a hierarchical distribution of knowledge and expertise across the broader helping professions.

By drawing on the construct of time and its powerful assumptions about prescriptivity and progression, participants were able to locate their grief along a sequential timeline that was further resourced by dominant stage theories of grief. Stage theories of grief (e.g. Kubler-Ross, 1969) have been criticised for their dominant assumptions that grief is normative and follows a prescriptive trajectory (see Breen & Connor, 2007). Participants' accounts reflected this 'normal' versus 'abnormal' dichotomy, particularly surrounding the expression of



grief. However, constructing their identity according to these assumptions also afforded speakers with a particular perspective on bereavement, which acted as a marker to other griever and engendered positions of experienced and inexperienced, respectively.

Participants' constructions illuminated the avoidance of grief explored in the context of interactions between the bereaved and their friends and families, which is in support of Jakoby's (2014) online survey findings. Going further, however, this study highlighted other avenues through which the avoidance of talking about death and bereavement may take place in unhelpful ways for those who are grieving. Avoidance was also seen to be enacted within professional contexts, which reinforced grief to be a topic that cannot be spoken about. In line with Walter (1999), these findings could be interpreted to represent societal mechanism of the 'policing' of bereavement; serving to reproduce dominant discourses in order to govern behaviour.

#### 4.1.2 Individualism

Dominant ideologies of individualism formed a second key discursive site within the accounts. This resonates with existing discursive literature (e.g. Valentine, 2008) and suggests that this discourse is available for bereavement outside of the context of the current study. Individualism afforded the participants in this study with greater power, as evidenced by constructions of grief as being unique to the individual, which allowed them to reject medicalised claims of universalism. The tensions created between medical and individualism discourses produced subjugated positions of having authority over one's own grief. This is a perspective that has been previously unexplored in the bereavement literature, the further examination of which could shed a useful light on ways to challenge the stigma of bereavement. This resource was also identified as differentiating cancer bereavement from other forms of loss, which further legitimised the specificity of grief in this context.

This study further highlighted how individualism produced self-regulatory social practices such as beginning to grieve before the death ('anticipatory grief'), which is a concept that has been well documented in the bereavement literature (Rando, 1986). This provides additional support to differentiate experiences of loss following a terminal illness such as cancer in comparison with other forms of loss. Offering a broader understanding of this, a key mechanism that appeared influence constructions of anticipatory grief in this study was the physical deterioration that participants witnessed as the cancer progressed, which was typically constructed as dehumanising in nature and was associated with the loss of their partner's identity. The formal diagnosis of terminal cancer also served to influence the experience of grief, which produced powerless subject positions.

However, drawing on individualism was also seen to engender expectations for speakers to take personal responsibility for their grief, which was reinforced by constructions of grief as an individual burden that others should be protected from. Totman and colleagues (2015) discuss this with respect to their participants in the context of a felt sense of pressure to be strong, which may be served by similar contextual influences. Similarly, this may offer an additional explanation as to why participants in previous studies (e.g. Dagget, 2002) reported struggling to share their grief with friends and families. Via normalisation and expectations of self-management (Foucault, 1977), speakers' constructions revealed the self-policing of the expression of grief that were tied up in stoicism and the practice of crying, which held diverging assumptions depending on gender. Gender distinctions in grief were reported in a number of studies investigating spousal bereavement (e.g. Brabant et. al., 1992; Kaunonen et. al., 2000). This study drew attention to the nuanced ways in which constructions of grief were co-resourced by discourses of individualism and discourses that are rooted in patriarchy, and which carry expectations for the emotional expression of males and females. Thus, this research highlights how multiple contextual influences can co-occur and compete to inform how individuals make sense of their experiences, which previous research in the field has left un-addressed.

The analysis identified points of resistance to the dominant assumptions held within individualism discourses, which enabled speakers to reject the privatisation of grief through being open and transparent with other people. In contrast to silenced positions, drawing on subjugated discourses engendered feelings of connectivity, producing empowering effects on subjectivity. This was constructed to be beneficial in the context of sharing experiences in a bereavement support groups and within some of the participants' existing social networks. Whilst mutual self-help groups have been suggested as representing a "counter culture" (Small & Hockey, 2001) in which attendees can relinquish themselves from traditional expectations (Walter, 1999), the finding that resistance from these expectations can be helpful within social relationships represented an unexpected finding not accounted for elsewhere in the literature. By adopting the position of 'experts by experience', individuals could challenge the dominating assumption that death and its response cannot be spoken about and were able to claim a certain authority over the non-bereaved as a result. This finding opens up new and interesting lines of enquiry that require further exploration.

#### 4.1.3 Productivity and Purpose

The final key site of discursive activity within the analysis reproduced the dominant assumptions underpinning a capitalist social structure, such as the expectation for individuals to contribute to economic growth and production of the state. Grief became problematised in speakers' accounts by rendering individuals as incapacitated and unproductive, which Harris (2009) suggests may marginalise the bereaved in society by representing a threat to the capitalist regime. The frequent reproduction of this discursive site throughout the accounts in this research are in strong support of Harris' claims, and may provide an illuminating explanation as to why individuals felt the need to 'keep busy' and 'be normal'. Specifically, it was found that in order to resist subjectivities of powerless, weak and useless as afforded by these constructions, individuals

attempted to keep busy and prioritise work. However this also served to prevent people from 'being with' their grief and had important implications for bereavement in people who are retired, which may offer a broader understanding of the specific challenges for spousal bereavement in older adults (see Naef et. al., 2013). While the notion of keeping busy and distraction from grief resonates with the previous studies to investigate the impact of spousal bereavement (e.g. Anderson & Diamond, 1995; Naef et. al., 2013), this represents a novel finding from a discursive perspective, which provides further insights into the underlying mechanisms within constructions of grief.

A specific nuance to this was the construction of marriage as an extra-discursive practice of purpose, which appeared to be disrupted by the loss of the relationship and the corresponding roles and identities within society that this affords (Jakoby, 2012; Bradbury, 1999). Constructions of grief in this context appeared to be resourced by patriarchal discourses and the power held within the institution of traditional marriage, highlighting the theoretical importance of attending to the material and discursive idiosyncrasies within these processes. This engendered diverging practices according to gender, particularly in terms of the decision to seek out new relationships following bereavement, a dilemma that has been raised in previous qualitative research (e.g. Lowe & McClement, 2010).

#### 4.1.4 Rhetorical Devices

Finally, by attending to the discursive level within the analysis, and to the presence and function of some of the linguistic techniques that were employed within participants' constructions, this study provides an additional insight at the 'micro level' of discourse (Holt, 2011). This highlighted how constructions could either serve to maintain individuality within participants' grief, or to unite the group in accordance with their shared identities in being bereaved spouses. It also created 'us' and 'them' distinctions between speakers and other non-bereaved individuals, which reinforced the assumption that other people cannot understand grief and loss. As a discursive practice, the use of humour was

employed at regular points within the conversations, which enabled connection within the discussions, which functioned to make talking about death and grief more manageable. This contributes further nuance within the bereavement literature illustrating how bereaved individuals construct grief in the context of their relationships with others.

The wider implications of these findings will be further considered in section 4.5.

## **4.2 Critical Evaluation**

In this section, the research will be subjected to evaluation and critique in relation to issues of quality assurance. The application of quantitatively associated constructs within the qualitative research domain remains a contested issue given its focus on meaning, subjective interpretation and the varying epistemological assumptions about 'truth', 'knowledge' and 'reality' that exist across qualitative methodologies (Yardley, 2000). Nonetheless, a number of authors have published guidelines (e.g. Yardley, 2000; Parker, 2004; Spencer & Richie, 2011), in an attempt to ensure that qualitative research retains a level of quality across epistemologies and methodologies. I have chosen to incorporate the principles outlined by Spencer and Richie (2011) in my evaluation of the current study, which will include consideration of credibility, contribution and rigour.

### **4.2.1 Credibility**

An important element of qualitative research concerns the plausibility of its claims and the adequacy with which interpretations have been made (Spencer & Richie, 2007). In an attempt to assess the credibility within this study, I presented my initial findings (and corresponding data extracts) to a clinical psychologist working within the collaborating bereavement service, so as to incorporate 'peer review' (Hammersley, 1992) into my evaluation. In addition to regular thesis supervision, I made use of peer supervision via an FDA discussion group, both of which

usefully enabled me to discuss my interpretations with others and reflect on alternative perspectives.

Whilst my intention is to provide participants with feedback of my key findings following its completed write-up and submission, time-constraints have prevented me from obtaining 'member-validation' (Angen, 2000), thus representing a limitation of the study. Acquiring participants' feedback, however, will inform a key element of my dissemination of the research.

#### 4.2.2 Contribution

Spencer and Richie (2011) consider contribution as referring to the value and relevance a piece of research holds, as applied to the development of theory, policy and practice within a given domain. By undertaking a discourse analytic approach, the current study goes beyond existing literature and contributes a greater understanding as to how the broader context informs constructions of grief and loss in spouses who have lost their partner to cancer.

The subjectivity inherent within any qualitative analysis renders generalisation beyond the immediacy of the research context problematic. However, from my own perspective, the accounts provided by participants in the study appeared reflective of those that typically occur in the support groups I have facilitated within the collaborating charity (although see section 4.3.3 for further discussion of this issue, with regards to the study's sample). Furthermore, it can be reasoned that if such constructions and practices relating to grief and loss are possible across three focus groups, the discourses that served to resource participants' constructions can be considered to be more broadly available within society (Willig, 2008).

The outcome from this research has in fact already informed a recent campaign that was launched within the current service. This was in response to the frequently reported absence of acknowledgement and understanding about grief

that exists within individuals' social networks, as emphasised within the current research. Further consideration to this will be given in section 4.4.

#### **4.2.3 Rigour and Transparency**

Given that notions of reliability and consistency are a problematic fit with certain forms of qualitative methodologies (due to the assumed subjectivity involved within interpretation), the concept of 'rigour' can be understood as the transparency through which pertinent aspects of the research process are disclosed (Yardley, 2000). I have attempted to address this issue by providing the reader with a certain level of transparency by outlining my approach to the process of analysis in chapter two, and presenting my analysis alongside specific extracts from the focus groups in chapter three. I additionally attempted to maintain a balance between the presentation of data extracts (provided by a range of participants) and their corresponding analytical text. This helped me to avoid the under or over-analysis of the data (Antaki, Billig, Edwards & Potter, 2003) and enabled me to adhere to the language contained in participants' accounts, and its function within their talk (Willig, 2008).

### **4.3 Reflexive Review**

#### **4.3.1 Personal Reflexivity**

Engaging in reflexivity is considered an essential process within discourse analytic research due to the contribution that the researcher's own constructions make within their interpretations (Willig, 2008). Post-structuralism asserts that because thought is tied up with language, reflexivity is continually captured and distorted by language (Descombes, 1980). Parker (1992) suggests that as a consequence, reflexivity itself is informed by wider discourses. With this in mind, I have aimed to bring an awareness of my personal and professional context so as to inform the reader of the factors influencing my engagement with this data (see chapter two).

As an additional aid, my use of a reflexive diary, in which I noted down my initial reflections following each of the focus groups and at points during my analysis, helped me to document my thinking about the role I took within the focus groups and the implications this had for subject positioning. Extracts from my diary can be viewed in Appendix K.

#### 4.3.1.1 *Power Dynamics within the Research*

Harper (2003) draws attention to the importance of developing a critically reflexive position so as to identify and address the effects of power relations on research process. Part of my rationale for choosing to collect my data within focus groups as opposed to individual interviews was to reduce the number of contributions I made to the discussions and subsequent influence over the data that I was collecting.

Nevertheless, I acknowledge that by initiating the research in the first place and inviting individuals to participate at a University location, I was already enacting the power differential that is implicit in the researcher-participant relationship (Ringer, 2013). This imbalance is enabled by the power that is afforded to the production of scientific research (Foucault, 1972), which could be seen to position me as a 'knowledgeable' representative of the field of bereavement. My open connection to the charity through which recruitment for the study took place further served to engender this perception.

Such assumptions about my role were evident in numerous ways during the focus group sessions. Firstly, there was an expectation for me to initiate the discussion, which was unavoidable given the design of the study. However, I additionally noted the acknowledgement of my role by participants at certain points, when I was directly addressed with a question about what is to be expected within bereavement, which immediately positioned me as an expert to whom they could consult. I deemed this to be pertinent, particularly given some of the key findings from my analysis, which highlighted how the



professionalisation of grief can subject people to an inferior position in comparison.

#### 4.3.1.2 *Undertaking a Foucauldian Discourse Analysis*

In the absence of any specific 'instructions' for how to approach a Foucauldian based discourse analysis (Graham, 2005), I am aware that the way in which I engaged with this analysis is informed by my nuanced interpretation both of the data and the Foucauldian principles which served to underpin this. Having never undertaken this approach before, an important part of this process involved developing my understanding of Foucault's key ideas, and becoming more familiar with the post-structuralist approach in which these sit. As part of this process I became increasingly aware of the political stance that FDA takes, and how this informs identification of the power differentials within social and institutional practices via the reproduction of discourses (Fairclough, 1992).

As was alluded to in chapter two, my interpretations are strongly informed by my learning experiences as a trainee, which include the exposure to a de-medicalising approach to human distress and a strong focus on the role of power. My training experiences have additionally provided me with greater awareness of the power differentials that are inherent within gender constructs, which will have likely served as an additional influence on my engagement with the analysis. As a result I considered the assumptions within the FDA approach to be a good 'fit' with my own position. However, in acknowledgement of the fact that other audiences may not share this stance, I reflected on how my participants in particular would receive my interpretations of their conversations, and the extent to which they were as aware of the intentions of the FDA approach. Specifically, I wondered how individuals would respond to being identified as being in a 'passive' position, or whether my interpretations relating to gender roles and their implications for new relationships could lead participants to feel invalidated. Adopting a critical reflexivity during the analysis has been, and will continue to be a crucial process as I prepare my research for publication.

#### 4.3.1.3 *The Focus Group Context*

Via its examination of interaction and co-construction between participants, the focus group has been suggested as being more likely to represent wider populations than the individual interview (Willig, 2008). Correspondingly, there were frequent points across the three focus groups in which speakers were highly engaged in interaction. I have attempted to capture some of the group interaction within the extracts selected to feature in the analysis, which highlight participants' co-constructions about grief and loss.

Interestingly, however, in many of the key accounts individual speakers spoke for relatively long periods of time before others' contributions were made. In order to address the specific research aims, and to avoid including overly long extracts, it was necessary to include extracts that featured less interaction.

Reflecting on my observations during the session and during the transcription and analysis phases, the relative absence of interaction often occurred at points when speakers were talking about particularly distressing aspects of their experiences. Given some of the key findings from the study, I wondered whether the assumption that grief is an individual experience produced particular social practices during the discussions, whereby everyone had their own story to tell as individuals.

#### 4.3.1.4 *Diversity Within the Sample*

The twenty-three individuals who took part in this research represented a relatively homogenous group with regards to their demographic information. Of predominantly white British heritage and, with the exception of one participant, aged fifty and above, the sample reflected a particular generation within a traditionally British culture, which was mirrored in their contributions. This represents an interesting nuance to the study, particularly given the breadth of existing literature, which has taken more of a focus on cultural diversity and the

impact of individualistic versus collectivistic societies within the context of bereavement (see Valentine, 2009). While cultural diversity was not a specific focus of the current study, the relatively small contribution made by individuals from non white-British backgrounds mean the implications of the study may have limited significance for grief and loss in other cultural contexts.

There are a number of possible explanations for the lack of cultural diversity within this study, the first of which may reflect divergence across cultures in terms of the value of attending a research focus group. Furthermore, the perceived benefit in accessing group support may also be limited to particular cultural groups, which has implications for my strategy of recruitment. Given previous research, cultural diversity within grieving practices may mean that individuals belonging to non-British groups are more likely to limit the expression of grief to within the family, or within their wider community.

Similarly, the findings from this study illustrated how constructions of grief and loss in spouses were powerfully informed by patriarchal discourses and the dominant assumptions held within the institution of traditional marriage. However, the contributions made within the discussions lacked perspective from representatives of LGBT communities, for whom the grief and loss of a partner may be constructed differently. The further influence of an individual's age may also be an important consideration. In thinking about the demographics of the sample during my analysis, I wondered whether the availability of alternative discourses could afford people with different ways-of-being, and how the operation of power may serve to shape this.

#### 4.3.2 Epistemological reflexivity

In addition to personal reflexivity, Willig (2013) highlights the importance of reflecting on the epistemological and methodological assumptions that underpin the research so as to consider what has been enhanced and obscured by adopting a given approach.

By adopting a social constructionist position, this research conceptualised grief and the loss of a partner as constructed through the cultural discourses that are made available and drawn upon through communication (Burr, 2003). Unlike the vast majority of existing bereavement research, which as a result of its positivist positioning, result in claims of ‘uncovering’ a ‘truth’, this research acknowledges the multiplicity of ‘knowledges’ that are the result of a diversity of perspectives and realities (Willig, 2008).

Parker (1992) has argued that discursive activity can be influenced by material ‘reality’. As such, a frequent criticism of a purely relativist position is that it prevents exploration of important non-discursive factors such as embodiment, which may limit and constrain how a given phenomenon (especially death) are constructed (Sims-Schouten et. al., 2007). In awareness of this, the incorporation of critical realism within this study sought to address this issue, enabling the additional acknowledgement of the materiality of death and its influence and deployment within participants’ discursive constructions of grieving and loss.

However, as Harper (2011) points out, there is on-going debate as to whether the alignment of critical realism within social constructionist research can lead to inconsistencies, particularly when different phenomena within the same analysis are selectively underpinned by different assumptions. Whilst it allowed for the materiality of death, this positioning would also make assumptions about the existence and nature of grief, which would make alternative claims about the existence and nature of bereavement.

My decision to use a discursive approach was largely in response to the relative minority of research to adopt this methodology within the bereavement literature. However, while addressing the aims of the current research, it is acknowledged that adopting this approach also limited the possibilities of what could be ‘found’. Specifically, by predominantly focusing on the influence of discourse on language

and sense-making, FDA has received criticism for failing to account for individual agency within subjectivity and how experience is constructed (Willig, 2013), positioning participants as passive recipients of discourse. In contrast, by attending to the rhetorical level of language, bottom-up approaches like DP take a better account of how individuals become active agents in using language to construct meaning involved in a given phenomenon and relating to their subjective experience. In recognition of what could be lost or obscured by taking an FDA approach, I decided to additionally examine the linguistic tools employed by participants. However, it is acknowledged that by focusing predominantly on 'macro-level' influences within loss and bereavement, the meaning within subjectivity could be minimised in comparison with broader contextual factors involved in this.

#### **4.4 Directions for Future Research**

This study explored the influence of material and discursive factors specific to spousal bereavement by cancer. This has produced a number of interesting findings that open up potential new lines of enquiry within the field, that warrants further attention. Whilst this research makes a valuable contribution to existing literature, discursive approaches within the bereavement context currently remain a minority. Broadly speaking then, future research carried out using similar approaches, and within the same epistemological bracket, would provide richer insights into the discursive influences that function to shape how bereavement is experienced.

Specifically, as acknowledged in section 4.3, the study's sample represented a particular demographic of predominantly white middle class individuals of a certain age group. Whilst this has produced a useful and idiosyncratic insight into this subsection of society, more research to address the influences of culture and sexuality on the constructions of this form of loss would be useful. This may help to draw out alternative discursive repertoires that are available in society, in order

to generate a richer and contextualised understanding of the loss of a spouse in this context.

Going further, exploration of the mechanisms that function to differentiate cancer bereavement from other forms of loss such as sudden death, or suicide would also provide greater nuance in the understanding of bereavement. For example, this research has highlighted how bereavement is frequently constructed within a medicalised framework, which could relate to the often highly medicalised setting in which cancer experiences take place. Future research questions could address the discursive influence on spousal bereavement, when the experience of death occurred outside of this context. For example, do other forms of loss draw on different discourses that impact on how bereavement is constructed? Equally, discursive approaches to investigating the impact the loss of other relationships following cancer would also make an interesting contribution to the development of new theoretical perspectives.

Finally, the findings from the current study call for further examination of spousal bereavement from cancer from a discursive perspective, so as to generate a richer understanding of bereavement in these contexts. However, given their difficulty in making generalisable claims, it is also important to acknowledge the relatively limited impact that such approaches have in affecting change on a broader level. Consequently, having influence at the policy level would require much larger-scale research, which may be better achieved via the implementation of quantitative methodologies (and thus a shift in epistemological positioning). In recognition of this, therefore, a necessary future direction for research may be to examine bereavement experiences on a wider scale, for example via the use of survey strategies, which could be distributed across a range of settings and platforms. The findings from the current study could be used to inform the development of such surveys, therefore strengthening alternative perspectives within research.

## **4.5 Implications for Clinical Practice and Bereavement Support**

### **4.5.1 Implications for Clinical Practice**

The findings from this study raise a number of important issues regarding clinical practice within the context of cancer bereavement. These highlight a range of implications for bereaved individuals themselves, and for the structure and provision of its support in this country.

#### **4.5.1.1 *Improving support within palliative care***

These findings contribute to existing claims which suggest that bereavement following cancer may represent a specific form of loss that is associated with unique challenges (see Fasse et. al., 2014), particularly for spouses who commonly adopt the palliative caregiving role (e.g. Gauthier & Gagliese, 2012). Specifically, in constructing their bereavement, participants in this study alluded to the impact of the deterioration they witnessed in their loved ones as the cancer progressed, the meaning behind a terminal diagnosis and having to navigate factors of uncertainty and hope throughout this process. Crucially then, there is a need to update the theoretical perspectives that underpin bereavement support in this area, given suggestions that bereavement interventions remain largely acontextual and do not account for the specificities in cancer bereavement (MacKinnon et al, 2013). As a key skill of their training, Clinical Psychologists could make a valuable contribution to this, via the development and implementation of new research.

Furthermore, developments in policy, such as the Supportive and Palliative Care for Adults with Cancer guidelines (NICE, 2004) highlight the need for bereavement support to be implemented within this context. However, some participants reported their struggle in being able to access this, which may suggest that individuals requiring input could slip through the net following their loss. Therefore there is also a need to improve links between mainstream support and palliative care and other end-of-life services, to ensure that

individuals have immediate and consistent access to appropriate support for the specific impact of cancer-related loss, as and when it is needed.

Clinical psychology may be usefully positioned to bridge this gap, by developing effective links with other services, including liaison with clinicians and volunteers within third sector organisations such as the charity collaborating in the current research. Clinical psychology may be of further use in implementing an integrated approach within end-of-life contexts, by contributing new perspectives to the typically medicalised approach to death and dying (Valentine, 2008). This could provide those caring for a terminally ill loved one with on-going support during the dying process and through the transition to bereavement. At the level of the individual, psychologists should be aware of the dominant assumptions that can often surround bereavement and acknowledge how these can lead people to hold expectations of how they 'should' grieve. Therefore, validation of those experiences of grief that deviate from normative and prescriptive expectations may enable people to make sense of their experiences in more meaningful ways. Furthermore, clinicians who are working with bereaved individuals should be careful to attend to the language (such as 'saying goodbye') used within clinical interactions. Incorporation of de-constructive and narrative approaches may be useful frameworks to guide non-directive and person-centred therapeutic conversations.

Going further, however, greater emphasis should also be placed on delivering interventions beyond the individual and within the wider palliative context in which many individuals bereaved by cancer begin their experiences.

Psychologists working within palliative and hospice settings would be usefully placed to offer of an alternative to the medicalised perspective, which may be of additional benefit for the staff teams working in these settings. Again, the implementation of narrative approaches to grief such as Michael White's 'Saying hullo again' (White, 1988) and dissemination of the alternative assumptions held within the 'Continuing Bonds' model (Klass et. al., 1996) within the medical



systems could open up thinking and positively impact the way in which individuals are supported. Through vehicles such as supervision and consultation, reflective practice, and attending regular MDT meetings across sectors, the provision of clinical psychology within these services could affect positive change across multiple levels of systems.

#### *4.5.1.2 Improving awareness of bereavement in frontline services*

One participant in this study described unhelpful experiences in their interactions with professionals working in front line services such as GPs and primary care staff and other accounts not included in the extracts also made reference to this. These professionals play a crucial role in ensuring that bereaved individuals get access to the most appropriate care outside of the palliative care context. This is especially important given the absence of a unifying policy that informs GP practice in the context of bereavement (Saunderson, Ridsdale & Jewell, 1999). There is therefore a fundamental need to develop further training in bereavement as informed by a range of alternative and contextual perspectives that were outlined in chapter one. However, rather than limiting the responsibility for this to within the 'expertise' of certain professionals, this study draws attention to the potential benefit in encouraging bereaved individuals to take up the position of 'expert by experience', whose subjective experience may afford professionals with helpful insights.

#### *4.5.1.3 The provision of alternative support*

Clearly, for some individuals, the extent of the distress caused by bereavement warrants professional input and it is therefore important to acknowledge the important role professionals will continue to be required to play within this field. However, key findings from this study additionally caution against the over-professionalisation of grief, which may have unhelpful implications for the bereaved. For example, the assumption that grief is always unmanageable and in need of professional support may serve to problematise the bereavement response. Further, locating responsibility for grief management within certain

professions (particularly those within a medicalised context) may reinforce societal assumptions that mourning a loved one cannot be supported within lay arenas, and perpetuate the social practices of not talking about grief. This supports arguments made previously that the location of expertise within professionals is restrictive of individual agency and prevents wider society from being able to offer the bereaved support themselves (Glaser & Strauss, 1965; Hockey, 2009).

In contrast to the formalised and prescriptive approach underpinning many bereavement interventions, many participants in this study found benefit in sharing their experience with others who were bereaved, or in feeling able to open up with friends and family around them. This finding suggests that, for some, bereavement may be better supported within existing relationships and via peer-support contexts such as mutual self-help groups. This may also be achieved within online communities and via social media, which represent additional and points of access for many people who are seeking connection and shared experience with other people.

Furthermore, taking bereavement out of the medicalised mental health sector and placing it within the community context may help to relinquish the problematised assumptions about grief. For these reasons, there is an additional need to develop the provision of services of this nature, in order to offer people the choice of a range of support across multiple platforms and in accordance with individual need.

#### 4.5.2 Implications for Public Awareness

Despite the issues raised above, in line with existing discursive research (Valentine, 2008), this study illuminates the power of the taboo of death that permeates society and the associated fear and avoidance of grief that is frequently enacted as a consequence. The accounts provided by participants highlight the nuanced ways in which this shapes expectations for individuals to

hide their grief and take personal responsibility for the response they have to death.

Whilst the provision of mutual self-help groups is clearly beneficial within bereavement support, it may not be addressing the potential marginalisation that is afforded to bereaved individuals in society as a whole (Harris, 2009) and fails to address some of the underlying mechanisms through which grieving is problematised in this culture. On a broader level, these findings point to the need to shift societal assumptions about bereavement. This would involve challenging the widespread fear and avoidance that surrounds the topic of death so as to open up the potential for grief to be shared more openly within their existing networks.

It is acknowledged that societal-level change represents a significant challenge requiring the power of a collective approach. However, initiatives such as the recent campaign developed by the current and collaborating service represent a positive step in the attempt of this. By raising awareness about the dominating silence that surrounds the topic of death and the impact this can have for the bereaved, it aims to encourage members of lay society to question their assumptions about bereavement, so that they may be better able to support those in their networks who have lost a loved one. Another important contribution comes from the National Council for Palliative Care (NCPC, 2016), whose campaign 'Dying Matters' has similar aims in helping people to talk more openly about death. Clinical psychology may further contribute to raising awareness across a range of influential forums, including influencing media portrayals of loss and bereavement. Specifically, their valuable skills in communication, formulation, public sector liaison and relative position of power place psychologists in an ideal position to advocate for change and voice alternative understandings of bereavement across contexts.

## **4.6 Conclusions**

This study adopted a discursive approach to the analysis of spouses' constructions of grief following loss to cancer. The research contributes to the development of existing literature that seeks to explore the lived experiences of cancer bereavement in this population. However, by employing this particular methodological line of enquiry, the study's findings offer an additional perspective on this phenomenon, affording further interpretation of the influence of the broader context within this.

In addressing each of the research questions I have drawn attention to the way in which constructions of grief and loss are resourced by a range of discourses. Furthermore, the study has demonstrated how these discourses can be conflicting and mutually fulfilling, producing 'acceptable' and 'unacceptable' grieving practices. Most notable were the constructions that located grief as a personal burden, which were reinforced by an avoidance of death, which could serve to silence participants within their social networks.

These findings highlight the significant challenges involved in the loss of a loved one and emphasise the importance of understanding the broader mechanisms within professional and societal responses to death. This raises interesting questions regarding the location of responsibility for bereavement within society, and point to the need to challenge problematic assumptions about death and bereavement in multiple contexts.

## 5. REFERENCES

Agnew, A., Manktelow, R., & Donaghy, K. (2008). User perspective on palliative care services: Experiences of middle-aged partners bereaved through cancer known to social work services in Northern Ireland. *Practice*, 20, 163-180.

American Psychiatric Association. (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). Washington D.C: American Psychiatric Association.

Anderson, M. (2001). You have to get inside the person” or making grief private: image and metaphor in the therapeutic reconstruction of bereavement. In J. Hockey, J. Katz, & N. Small. (Eds). *Grief, Mourning and Death Ritual* (pp. 135-143). Buckingham, Philadelphia: Open University Press.

Anderson, K. L., & Dimond, M. F. (1995). The experience of bereavement in older adults. *Journal of Advanced Nursing*, 22(2), 308-315.

Angen, M. J. (2000). Evaluating interpretive inquiry: Reviewing the validity debate and opening the dialogue. *Qualitative Health Research*, 10, 378-395.

Antaki, C., Billig, M., Edwards, D., & Potter, J. (2003). Discourse Analytic Shortcomings Discourse Analysis Online, 1. Retrieved April 7th, 2016, from <http://extra.shu.ac.uk/daol/articles/open/2002/002/antaki2002002-paper.html>

Arribas-Ayllon, M., & Walkerdine, V. (2008). Foucauldian Discourse Analysis. In C. Willig & W. Stainton-Rogers (Eds.), *The Sage handbook of qualitative research in psychology* (pp. 91-108). London: Sage Publications.

- Asai, M., Fujimori, M., Akizuki, N., Inagaki, M., Matsui, Y., & Uchitomi, Y. (2010). Psychological states and coping strategies after bereavement among the spouses of cancer patients: a qualitative study. *Psycho-Oncology*, 19(1), 38-45.
- Banister, P. (2011). *Qualitative Methods in Psychology: A Research Guide*. McGraw Hill Education (UK).
- Barnett, C. (2005). The consolations of 'neoliberalism'. *Geoforum*, 36, 7-12.
- Brabant, S., Forsyth, C. J., & Melancon, C. (1992). Grieving men: thoughts, feelings, and behaviors following deaths of wives. *Hospice Journal*, 8, 33-47.
- Bradbury, M. (1999). *Representations of Death: A Social, Psychological Perspective*. London: Routledge.
- Breen, L. & Connor, M. (2007). The fundamental paradox in the grief literature: A critical reflection. *Omega*, 53, 199-219.
- Burr, V. (2003). *Social Constructionism*. (2nd ed.). London: Routledge.
- Cancer Research UK (2016). Retrieved May 14th From <http://www.cancerresearchuk.org/health-professional/cancer-statistics/incidence/all-cancers-combined>
- Caserta, M. S., Utz, R. L., & Lund, D. A. (2013). Spousal bereavement following cancer death. *Illness, Crisis & Loss*, 21, 185-202.
- Cromby, J., & Nightingale, D.J. (1999). What's wrong with social constructionism? In D.J. Nightingale & J. Cromby (Eds.), *Social*

*Constructionist Psychology: A Critical Analysis of Theory and Practice* (pp. 1-19). Buckingham: Open University Press.

Daggett, L. M. (2002). Living with loss: Middle-aged men face spousal bereavement. *Qualitative Health Research*, 12, 625-639.

Davidson, K. (2001). Late life widowhood, selfishness and new partnership choices: a gendered perspective. *Ageing and Society*, 21, 297-317.

Davis, C. G., Nolen-Hoeksema, S., & Larson, J. (1998). Making sense of loss and benefiting from the experience: two construals of meaning. *Journal of Personality and Social Psychology*, 75, 561.

Descombes, V. (1980). *Modern French Philosophy*. Cambridge: Cambridge University Press.

DiGiacomo, M., Lewis, J., Nolan, M. T., Phillips, J., & Davidson, P. M. (2013). Transitioning from caregiving to widowhood. *Journal of Pain and Symptom Management*, 46, 817-825.

Doka, K. J. (Ed.). (1989). *Disenfranchised Grief: Recognizing Hidden Sorrow* (pp.311). Lexington, MA: Lexington Books.

Dumont, I., Dumont, S., & Mongeau, S. (2008). End-of-life care and the grieving process: family caregivers who have experienced the loss of a terminal-phase cancer patient. *Qualitative Health Research*, 18, 1049-1061.

Edwards, D., Ashmore, M., & Potter, J., (1995). Death and furniture: The rhetoric, politics and theology of bottom line arguments against relativism. *History of the Human Sciences*, 8, 25-49.

- Engle, G. L. (1961). Is grief a disease? A challenge for medical research. *Psychosomatic Medicine*, 23, 18-22.
- Fairclough, N. (1992). *Discourse and Social Change*. Cambridge: Polity Press.
- Fasse, L., Sultan, S., Flahault, C., MacKinnon, C. J., Dolbeault, S., & Brédart, A. (2014). How do researchers conceive of spousal grief after cancer? A systematic review of models used by researchers to study spousal grief in the cancer context. *Psycho-Oncology*, 23, 131-142.
- Finlay, L., & Gough, B. (2003). *Reflexivity: A practical guide for researchers in health and social sciences*. Oxford: Blackwell.
- Foucault, M. (1972). *The Archaeology of Knowledge*. London: Tavistock.
- Foucault, M. (1976). *The birth of the clinic. An Archaeology of Medical Perception*. Retrieved from [https://monoskop.org/images/9/92/Foucault\\_Michel\\_The\\_Birth\\_of\\_the\\_Clinic\\_1976.pdf](https://monoskop.org/images/9/92/Foucault_Michel_The_Birth_of_the_Clinic_1976.pdf)
- Foucault, M. (1977). *Discipline and Punish. The Birth of the Prison*. Harmondsworth: Penguin.
- Foucault, M. (1978). *The History of Sexuality: An Introduction*. Harmondsworth: Penguin.
- Foucault, M. (1982). The Subject and Power. In H.L. Dreyfus & P. Rabinow (Eds.), *Michel Foucault beyond structuralism and hermeneutics* (pp. 208-26). New York: Harvester Wheatsheaf.



- Foucault, M. (1985). *Discourse and Truth. The Problematization of Parrhesia*. Retrieved from <http://www.naturalthinker.net/trl/texts/Foucault,Michel/Foucault%20%20Discourse%20and%20truth.pdf>
- Foucault, M. (1988) 'Technologies of the Self'. In L. H. Martin, H. Gutman, & P. H. Hutton. (Eds.). *Technologies of the Self: A Seminar with Michel Foucault, October 25, 1982* (pp. 16–49). Amherst: The University of Massachusetts Press.
- Freud, S. (1917). Mourning and melancholia. In *A General Selection from the Works of Sigmund Freud*. NY: Doubleday Anchor Books.
- Frith, H., & Gleeson, K. (2011). Qualitative data collection: Asking the right questions. In D. Harper, & A. R. Thompson, (Eds.). (2011). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners*, 55-67.
- Gauthier, L. R., & Gagliese, L. (2012). Bereavement interventions, end-of-life cancer care, and spousal well-being: A systematic review. *Clinical Psychology Science and Practice*, 19, 72-92.
- Germينو, B. B., Fife, B. L., & Funk, S. G. (1995, February). Cancer and the partner relationship: What is its meaning?. *Seminars in Oncology Nursing*, 11, 43-50.
- Gilbar, O., & Ben-Zur, H. (2002). Bereavement of spouse caregivers of cancer patients. *American Journal of Orthopsychiatry*, 72, 422-432.

- Gillies, J., & Neimeyer, R. A. (2006). Loss, grief, and the search for significance: Toward a model of meaning reconstruction in bereavement. *Journal of Constructivist Psychology, 19*, 31-65.
- Glaser, B. G., & Strauss, A. L. (1965). *Awareness of Dying*. Chicago: Aldine
- Golsworthy, R., & Coyle, A. (1999). Spiritual beliefs and the search for meaning among older adults following partner loss. *Mortality, 4*, 21-40.
- Graham, L.J. (2005). Discourse analysis and the critical use of Foucault. [Unpublished conference paper]. Retrieved November 2015 from <http://eprints.qut.edu.au/2689/1/2689.pdf>
- Guldin, M. B., Jensen, A. B., Zachariae, R., & Vedsted, P. (2013). Healthcare utilization of bereaved relatives of patients who died from cancer. A national population-based study. *Psycho-Oncology, 22*, 1152-1158.
- Hallam, E., Hockey, J., & Howarth, G. (2005). *Beyond the Body: Death and Social Identity*. Routledge.
- Hammersley, M. (1992). *What's Wrong with Ethnography?* London: Routledge.
- Harper, D.J. (2003). Developing a critically reflexive position using discourse analysis. In Finlay, L., & Gough, B. (eds.). *Reflexivity: A Practical Guide for Researchers in Health and Social Sciences* (pp. 78-91). Oxford: Blackwell Science.
- Harper, D.J. (2011). Choosing a Qualitative Research Method. In Harper, D., & Thompson, A.R. (eds.). *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 83-97). Chichester: Wiley-Blackwell.

- Harris, D. (2010). Oppression of the bereaved: A critical analysis of grief in western society. *Omega-Journal of Death and Dying*, 60, 241-253.
- Heath, J. A., & Ciscel, D. H. (1988). Patriarchy, family structure and the exploitation of women's labor. *Journal of Economic Issues*, 22, 781-794.
- Hochschild, A. R. (1979). Emotion work, feeling rules, and social structure. *American Journal of Sociology*, 551-575.
- Holland, J. C., Breitbart, W., Jacobson, C., Lederberg, M. S., Loscalzo, M. J., & McCorkle, R. (Eds.). (2010). *Psycho-Oncology* (2nd ed.). New York: Oxford University Press.
- Howitt, D. (2010) *Introduction to Qualitative Research Methods in Psychology*. Harlow: Prentice Hall.
- Hockey, J. (1996). Encountering the 'reality of death' through professional discourses: The matter of materiality. *Mortality*, 1, 45-60.
- Hockey, J. (2001). Changing death rituals. In Hockey, J., Katz, J., & Small, N. (Eds). *Grief, Mourning and Death Ritual*. (pp. 185-211). Buckingham, Philadelphia: Open University Press.
- Hockey, J. (2007). Closing in on death? Reflections on research and researchers in the field of death and dying. *Health Sociology Review*, 16, 436-446.
- Holt, A. (2011). Discourse Analysis Approaches. In Frost, N. (Ed.). *Qualitative research methods in psychology: From core to combined approaches*. (pp. 66-91). Maidenhead: Open University Press.

- Holtslander, L., & Duggleby, W. (2010). The psychosocial context of bereavement for older women who were caregivers for a spouse with advanced cancer. *Journal of Women & Aging, 22*, 109-124.
- Howarth, R. A. (2011). Concepts and controversies in grief and loss. *Journal of Mental Health Counseling, 33*, 4-10.
- Hudson, P. L. (2006). How well do family caregivers cope after caring for a relative with advanced disease and how can health professionals enhance their support?. *Journal of Palliative Medicine, 9*, 694-703.
- Illich, I. (1975). *Medical Nemesis: The Expropriation of Health*. London: Calder and Boyars.
- Jakoby, N. R. (2012). Grief as a social emotion: Theoretical perspectives. *Death Studies, 36*, 679-711.
- Johansson, Å. K., & Grimby, A. (2011). Anticipatory grief among close relatives of patients at hospice and palliative wards. *American Journal of Hospice and Palliative Medicine, 29*, 134-138.
- Kaunonen, M., Päivi, Å. K., Paunonen, M., & Erjanti, H. (2000). Death in the Finnish family: experiences of spousal bereavement. *International Journal of Nursing Practice, 6*, 127-134.
- Keegan, O., McGee, H., Hogan, M., Kunin, H., O'Brien, S., & O'Siorain, L. (2001). Relatives' views of health care in the last year of life. *International Journal of Palliative Nursing, 7*, 449-456.
- Klass, D. (1993). Solace and immortality: Bereaved parents' continuing bond with their children. *Death Studies, 17*, 343-368.

- Klass, D., Silverman, P. R., & Nickman, S. L. (1996). *Continuing Bonds*. Washington, DC: Taylor & Francis.
- Kleinman, A. (2012). Culture, bereavement, and psychiatry. *The Lancet*, 379, 608-609.
- Koop, P. M., & Strang, V. R. (2003). The bereavement experience following home based family caregiving for persons with advanced cancer. *Clinical Nursing Research*, 12, 127-144.
- Kubler-Ross, E. (1969). *On Death and Dying*. New York: Springer.
- Linderholm, M., & Friedrichsen, M. (2010). A desire to be seen: family caregivers' experiences of their caring role in palliative home care. *Cancer Nursing*, 33, 28-36.
- Lindemann, E. (1944). Symptomatology and management of acute grief. *American Journal of Psychiatry*, 101, 141-148.
- Lister, S., Pushkar, D., & Connolly, K. (2008). Current bereavement theory: Implications for art therapy practice. *The Arts in Psychotherapy*, 35, 245-250.
- Lowe, M. E., & McClement, S. E. (2011). Spousal bereavement: The lived experience of young Canadian widows. *OMEGA-Journal of Death and Dying*, 62, 127-148.
- Lupton, D. (1998). *The Emotional Self*. London: Sage.

- MacKinnon, C. J., Milman, E., Smith, N. G., Henry, M., Berish, M., Copeland, L. S., & Cohen, S. R. (2013). Means to meaning in cancer-related bereavement identifying clinical implications for counseling psychologists. *The Counseling Psychologist*, 41, 216-239.
- Malson, H. (1998). *The Thin Woman. Feminism, Post-structuralism and the Social Psychology of Anorexia Nervosa*. Great Britain: Routledge.
- Martin, T., & Doka, K. J. (1996). Masculine grief. In K. J. Doka (Ed.). *Living with Grief: After Sudden Loss, Suicide, Homicide, Accident, Heart Attack, Stroke*. (pp. 139 159.) Bristol, PA: Taylor & Francis.
- Mercer, J., & Feeney, J. (2009). Representing death in psychology: Hospice nurses' lived experiences. *Mortality*, 14, 245-264.
- Mossin, H., & Landmark, B. T. (2011). Being present in hospital when the patient is dying-a grounded theory study of spouses experiences. *European Journal of Oncology Nursing*, 15, 382-389.
- Myerhoff, B. (1982). *Life History Among the Elderly: Performance, Visibility and Remembering. A Crack in the Mirror: Reflexive Perspectives in Anthropology*, (pp. 99-117). Philadelphia: University of Pennsylvania Press.
- Naef, R., Ward, R., Mahrer-Imhof, R., & Grande, G. (2013). Characteristics of the bereavement experience of older persons after spousal loss: An integrative review. *International Journal of Nursing Studies*, 50, 1108-1121.
- National Council for Palliative Care. (2016) Retrieved May 2016 from: <http://www.dyingmatters.org/>

- Neimeyer, R. A. (2004). Research on grief and bereavement: Evolution and revolution. *Death Studies*, 28, 489-490.
- Neimeyer, R. A., Klass, D., & Dennis, M. R. (2014). A social constructionist account of grief: Loss and the narration of meaning. *Death Studies*, 38, 485-498.
- Neimeyer, R. A., Wittkowski, J., & Moser, R. P. (2004). Psychological research on death attitudes: An overview and evaluation. *Death Studies*, 28, 309-340.
- National Institute for Clinical Excellence. (2004). Improving supportive and palliative care for adults with cancer. Retrieved from <https://www.nice.org.uk/guidance/csg4>
- Olson, R. E. (2014). Indefinite loss: the experiences of carers of a spouse with cancer. *European Journal of Cancer Care*, 23, 553-561.
- Parker, I. (1992). *Discourse Dynamics: Critical Analysis for Social and Individual Psychology*. London: Routledge.
- Parker, I. (2004). Criteria for qualitative research in psychology. *Qualitative Research in Psychology*, 1, 95-106.
- Parkes, C. M. (2001). A historical overview of the scientific study of bereavement. In M.S. Stroebe, R.O. Hansson, W. Strobe, & H. Shut (Eds.), *Handbook of Bereavement Research: Consequences, Coping and Care* (pp. 25-45). Washington, DC: American Psychological Association
- Parkes, C. M. (2006). *Love and Loss: The Roots of Grief and its Complications*. London: Routledge.

- Payne, S., Smith, P., & Dean, S. (1999). Identifying the concerns of informal carers in palliative care. *Palliative Medicine*, 13, 37-44.
- Payne, S., Jarrett, N., Wiles, R., & Field, D. (2002). Counselling strategies for bereaved people offered in primary care. *Counselling Psychology Quarterly*, 15, 161-177.
- Potter, J. (1996). *Representing Reality: Discourse, Rhetoric and Social Constructionism*. London: Sage.
- Potter, J., & Wetherell, M. (1987). *Discourse and Social Psychology. Beyond Attitudes and Behaviour*. Bristol: SAGE.
- Ramon, S. (2000). Participative mental health research: Users and professional researchers working together. *Mental Health Care*, 3, 224-228.
- Rando, T. A. (1986). *Loss and Anticipatory Grief*. Lexington Books.
- Rando, T. A. (2000). *Clinical Dimensions of Anticipatory Mourning: Theory and Practice in Working with the Dying, Their Loved Ones, and Their Caregivers*. Research Press.
- Reynolds, J. J. (2002). Disenfranchised Grief and the Politics of Helping: Social Policy and its Clinical Implications. In K. J. Doka (Ed.), *Disenfranchised Grief: New Directions, Challenges, and Strategies for Practice*, 351-388.
- Riches, G., & Dawson, P. (1996). Communities of feeling: The culture of bereaved parents. *Mortality*, 1, 143-161.



- Ringer, A. (2013). Researcher-participant positioning and the discursive work of categories: Experiences from fieldwork in the mental health services. *Qualitative Studies*, 4, 1-20.
- Riessman, C. K. (2008). *Narrative Methods for the Human Sciences*. California: Sage.
- Root, B. L., & Exline, J. J. (2014). The role of continuing bonds in coping with grief: Overview and future directions. *Death Studies*, 38, 1-8.
- Rose, N. (1985). *The Psychological Complex*. London: Routledge.
- Saunderson, E. M., Ridsdale, L., & Jewell, D. (1999). General practitioners' beliefs and attitudes about how to respond to death and bereavement: qualitative study. Commentary: Use of personal experience should be legitimised. *British Medical Journal*, 319, 293-296.
- Seale, C. (1998). *Constructing Death: The Sociology of Dying and Bereavement*. Cambridge University Press.
- Silverman, D. (1997). Validity and credibility in qualitative research. In G. Miller & R. Dingwall (Eds.) *Context and Method in Qualitative Research: The Alternative Paradigm* (pp. 12-25). London: Sage Publications.
- Sims-Schouten, W., Riley, S.C.E., & Willig, C. (2007). Critical Realism in Discourse Analysis: A Presentation of a Systematic Method of Analysis Using Women's Talk of Motherhood, Childcare and Female Employment as an Example. *Theory & Psychology*, 17, 101-124.

- Sinding, C. (2003). "Because you know there's an end to it": Caring for a relative or friend with advanced breast cancer. *Palliative & Supportive Care*, 1, 153-163.
- Small, N. (2001). Theories of grief: a critical review. In J. Hockey, J. Katz, & N. Small. (Eds). *Grief, Mourning and Death Ritual*. (pp. 19-48). Buckingham, Philadelphia: Open University Press.
- Small, N., & Hockey, J. (2001). Discourse into practice: The production of bereavement care. In J. Hockey, J. Katz, & N. Small. (Eds). *Grief, Mourning and Death Ritual*. (pp. 97-124.) Buckingham, Philadelphia: Open University Press.
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomological Analysis: Theory, Method & Research*. London: Sage.
- Spencer, L. & Ritchie, J. (2011). In Pursuit of Quality. In D. J. Harper & A. R. Thompson (Eds.), *Qualitative Research Methods in Mental Health and Psychotherapy: A Guide for Students and Practitioners* (pp. 227-242). West Sussex: John Wiley & Sons Ltd.
- Stajduhar, K. I., Martin, W., & Cairns, M. (2010). What makes grief difficult? Perspectives from bereaved family caregivers and healthcare providers of advanced cancer patients. *Palliative and Supportive Care*, 8, 277-289.
- Stroebe, W. (1993). *Handbook of bereavement: Theory, Research, and Intervention*. Cambridge University Press.
- Stroebe, M. (2015). "Is Grief a Disease?" Why Engel Posed the Question. *OMEGA Journal of Death and Dying*, 71, 272-279.

- Stroebe, M. S., & Stroebe, W. (1993). The mortality of bereavement: A review. In S. Stroebe, W. Strobe, & R. Hansson. (Eds.) *Handbook of Bereavement: Theory, Research, and Intervention*. (pp. 175-196.) Cambridge University Press.
- Totman, J., Pistrang, N., Smith, S., Hennessey, S., & Martin, J. (2015). 'You only have one chance to get it right': A qualitative study of relatives' experiences of caring at home for a family member with terminal cancer. *Palliative Medicine*, 29, 496-507.
- Trudeau-Hern, S., & Daneshpour, M. (2012). Cancer's impact on spousal caregiver health: A qualitative analysis in grounded theory. *Contemporary Family Therapy*, 34, 534-554.
- Turner, V. W. (1975). *Dramas, Fields, and Metaphors: Symbolic Action in Human Society*. Cornell University Press.
- Valentine, C. (2006). Academic constructions of bereavement. *Mortality*, 11, 57-78.
- Valentine, C. (2008). *Bereavement Narratives: Continuing Bonds in the Twenty-First Century*. Routledge.
- Valentine, C. (2009). Continuing bonds after bereavement: a cross-cultural perspective. *Bereavement Care*, 28, 6-11.
- Waldrop, D. P. (2007). Caregiver grief in terminal illness and bereavement: A mixed methods study. *Health & Social Work*, 32, 197-206.
- Walter, T. (1996). A new model of grief: Bereavement and biography. *Mortality*, 1, 7-25.

Walter, T. (1999). *On Bereavement: The Culture of Grief*. McGraw-Hill Education (UK).

White, M. (1988). Saying hullo again: The incorporation of the lost relationship in the resolution of grief. *Dulwich Centre Newsletter*, 3, 29-36.

Willig, C. (1999). Beyond appearances: a critical realist approach to social constructionist work. In D. J. Nightingale, & J. Cromby. (Eds.) (1999). *Social Constructionist Psychology: A Critical Analysis of Theory and Practice* (pp. 37- 51). Guildford: OU Press.

Willig, C. (2001). *Introducing Qualitative Research in Psychology: Adventures in Theory and Method*. Buckingham: Open University Press.

Willig, C. (2008). *Introducing Qualitative Research in Psychology* (2nd ed.). Maidenhead: Open University Press.

Willig, C. (2011). Cancer diagnosis as discursive capture: Phenomenological repercussions of being positioned within dominant constructions of cancer. *Social Sciences & Medicine*, 73, 897-903.

Willig, C. (2013). *Introducing Qualitative Research Methods in Psychology*. (3rd ed.). Maidenhead: McGraw Hill/Open University Press.

Wong, W. K., & Ussher, J. (2009). Bereaved informal cancer carers making sense of their palliative care experiences at home. *Health & Social Care in The Community*, 17, 274-282.

- Wong, W. T., Ussher, J., & Perz, J. (2009). Strength Through Adversity: Bereaved Cancer Carers' Accounts of Rewards and Personal Growth from Caring. *Palliative and Supportive Care*, 7, 187-196.
- Worden, J. W. (1991). Grief counselling and grief therapy: A handbook for the mental health practitioner. (2nd ed). New York: Springer.
- Wortman, C. B., & Silver, R. C. (2001). The myths of coping with loss revisited: In. M. S. Stroebe, & R. O. Hansson (Eds.), *Handbook of Bereavement: Theory, Research, and Intervention*. Cambridge: Cambridge University Press.
- Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health*, 15, 215-228.
- Young, M. (1995). Black humour-making light of death. *Policing and Society: An International Journal*, 5, 151-167.

## **6. APPENDICES**

### **Appendix A: Outline of Literature Review**

Initially, my review began within publication databases PubMed, PsycINFO, PsycArticles and was extended to additional databases (Cinnall Plus, Academic Search Complete; SCOPUS and Science Direct). I was also informed by key references that I sourced from within relevant articles. Whilst the focus of my research is specifically on experiences of cancer bereavement in spouses, I wanted to ascertain more broadly how bereavement in general has been conceived in research. My search terms were developed following the use of the thesaurus on EBSCO, which highlighted any additional key words associated with a given term in the literature. My search terms included the combinations of the following concept clusters:

- Bereavement: 'grie\*', 'loss', 'mourning' and 'bereave\*';
- Death and dying;
- Cancer: including 'terminal cancer' and 'neoplasms'.
- I also incorporated 'spous\*' and 'partner' into my searches.

Additional searches were performed in anticipation of the employed methodology and included the following:

- 'Discourse' or 'discourse analysis'

I limited my findings to English; qualitative and filtered out non-adult populations. Additional parameters were included by restricting searches to specific subject headings (such as 'palliative care') within the databases, due to the significantly large numbers yielded in response to these searches. Papers were selected by scanning the abstracts. Articles that were deemed relevant were incorporated into an excel spreadsheet.

## **Appendix B: Ethical Approval Letter from the University of East London**

## NOTICE OF ETHICS REVIEW DECISION

### For research involving human participants

BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

**SUPERVISOR:** Neil Rees      **REVIEWER:** Jemma Harris

**STUDENT:** Francine Bear

**Title of proposed study:** Exploring the social construction of grief and loss in spouses following bereavement by cancer

**Course:** Professional Doctorate of Clinical Psychology

**DECISION** (*Delete as necessary*):

**\*APPROVED, BUT MINOR CONDITIONS ARE REQUIRED BEFORE THE RESEARCH COMMENCES**

**APPROVED:** Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

**APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES** (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

**NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED** (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

**Minor amendments required** (*for reviewer*):

The researcher should discuss with her supervisor alternative provisions for non-English speakers- should any get in touch. For example, sourcing support groups/resources that might be available in a range of other languages so that, in the rare cases where such individuals might respond to the study adverts, such individuals do not feel completely excluded.

**Major amendments required** *(for reviewer):*

**Confirmation of making the above minor amendments** *(for students):*

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name *(Typed name to act as signature): Francine Bear*

Student number:

Date: 01.05.15

**ASSESSMENT OF RISK TO RESEACHER** *(for reviewer)*



If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

☒

MEDIUM

☐

LOW

*Reviewer comments in relation to researcher risk (if any):*

The application states that interviews might occasionally take place in participants' homes. The application states that arrangements have been made with the study supervisor/Director of Studies to minimise risks and to ensure that the researcher's whereabouts is known.

**Reviewer** (*Typed name to act as signature*):

Jemma Harris

**Date:** 1.5.15

*This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)*

**PLEASE NOTE:**

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

\*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here:

<http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

**Appendix C: Ethical Approval Letter from the Voluntary Service**

Name of Service

December 2014

**To Whom It May Concern,**

On behalf of the Charity Board for [name of the service], we agree to allow Francine Bear to advertise and recruit from our population and beneficiaries for the purposes of her DClinPsy research.

Yours sincerely,

X

[Dr Clinical Psychologist]

Director of [Bereavement service]

*Registered charity number: \*\*\*\*\**

## **Appendix D: Interest in Participation Survey**

Registering your interest in a focus group related to cancer bereavement

Please answer the following questions.

1. Would you like to register your interest to take part in a one-off focus group? (There is an opportunity to ask questions below).

☐ Yes

☐ No

2. Have you been bereaved by cancer?

☐ Yes

☐ No

3. Which of the following best describes your relationship with the person who has died? (As a reminder the purpose of this study involves inviting people whose husband, wife or partner died from cancer).

☐ Husband

☐ Wife

☐ Civil Partner

☐ Other (please describe)

4. How long ago did your loved one die?

Years

Months

5. Please provide the following information

Please enter your full name

Please enter your email address

Please enter a contact number

6. How would you preferred to be contacted about this research?

☐ By email

☐ By telephone

☐ Either email or telephone

7. Do you have any questions? Please use the box below.

## Appendix E: Participant Invitation Letter

**UNIVERSITY OF EAST LONDON**

School of Psychology

Stratford Campus  
Water Lane  
London E15 4LZ

**The Principal Investigator**

Francine Bear

Email: [Charity email address]

Mobile: xxxxxxxxxxxx

**Consent to Participate in a Research Study**

The purpose of this letter is to provide you with the information that you need in order to consider whether to participate a research study. The study is being conducted as part of my Professional Doctorate in Clinical Psychology degree at the University of East London.

**Project Title**

How is grief and loss talked about by husbands, wives and partners following bereavement by cancer?

**What is the project about?**

Increased incidence rates in cancer mean that more and more people will likely be bereaved by cancer every day in the UK. Research suggests that losing your husband, wife or partner to cancer brings unique challenges that affect experiences of grief. However, bereavement research has tended to focus on the difference between 'normal' and 'abnormal' grief, with many popular psychological theories implying that grief progresses through certain stages or phases. However, bereavement may be very different for different people, and so these theories may not always be helpful for everyone. Far less is understood about people's lived experiences of this kind of loss, specifically, or how people make sense of these experiences with others around them.

By finding out more about cancer bereavement from the perspective of the bereaved, including hearing about their interactions with friends, families and professional helpers, this project hopes to better inform how individuals should be best supported, both professionally and by others in society.

I am interested in exploring the ways in which people who are bereaved following cancer talk about and make sense of their experiences of loss and grief with one another. I hope to understand how dominant messages that exist within society may influence this and how people may be perceived in society following their loss.

**What will I be asked to do?**

The research involves attending a focus group with other people who have lost their partner or spouse to cancer. You will be asked to share your thoughts and experiences together as guided by some broad questions that I will put to the group.

There are no risks involved in taking part in the focus group, however it is possible, given the sensitivity of the research topic that you could become upset when talking about your experiences. This is both a common and understandable reaction and a member of [Bereavement charity] will be available for the duration of the focus group to support you with this, or provide you with any information that you may need. You will be free to take a break from the group at any time. Alternatively, you may withdraw from the research at any time, without having to give a reason, and with no disadvantage to you.

You are not obliged to tell anyone at [Bereavement charity] about your involvement in this research, and your participation will have no impact on your access to the support that the charity offers.

### **How will my information be kept safe and confidential?**

In order to analyse the information discussed in the focus group I will need to audio record it. I will then transcribe the recording into a typed document. I will be the only person to listen to the recording. When I transcribe the recording, your name, the names of anyone you refer to and any other details that might identify you or your family members will be changed to protect your anonymity. Transcripts may also be read by my research supervisor [Dr Neil Rees] at the University of East London and by the examiners who mark my research.

The audio recordings will be kept on an encrypted file on my password-protected computer and on an encrypted hard-drive device. This information will not be shared with anyone else other than the researcher. Following completion of the research this information will be destroyed.

Written transcripts will be kept in a separate encrypted file on my password-protected computer and on an encrypted hard-drive device. These will be kept for up to three years after the completion of the research and may be used for publication.

Your name and contact details will be stored in a separate file on my password-protected computer. The contact details you provide when you register your interest will be stored for the duration of the research, after which this information will be destroyed.

### **Where will the focus groups take place?**

The focus group will take place at University Square Stratford, East London. More information about the venue including travel directions will be provided.

### **Will I receive anything for taking place?**

It will not be possible to pay you for your participation in the research.

### **Disclaimer**

You are not obliged to take part in this study and should not feel in any way forced to participate. You are free to withdraw at any time. Should you choose to withdraw from the study you may do so without disadvantage to yourself and without any obligation to give a reason. Since your participation involves group discussions, should you withdraw, I will not be able to remove your information from the audio recording and may refer to your anonymised contributions in the analysis and write-up of the research.

Please feel free to ask me any questions. If you are happy to continue you will be asked to sign a consent form prior to your participation. Please retain this invitation letter for reference.

If you have any questions or concerns about how the study has been conducted, please contact one of the following:

- Study supervisor: Dr Neil Rees, School of Psychology, University of East London, Water Lane, London E15 4LZ. Telephone. [Neil.Rees@uel.ac.uk](mailto:Neil.Rees@uel.ac.uk)
- Chair of the School of Psychology Research Ethics Sub-committee: Dr. Mark Finn, School of Psychology, University of East London, Water Lane, London E15 4LZ.  
(Tel: 020 8223 4493. Email: [m.finn@uel.ac.uk](mailto:m.finn@uel.ac.uk))

Thank you in anticipation.  
Yours sincerely,

Francine Bear – August 2015

## **Appendix F: Participant Consent Form**

### **CONSENT FORM**

### **UNIVERSITY OF EAST LONDON**

## **Consent to participate in a research study**

### **How is grief and loss talked about by spouses and partners following bereavement by cancer?**

I have the read the information sheet relating to the above research study and have been given a copy to keep. The nature and purpose of the research have been explained to me, and I have had the opportunity to discuss the details and ask questions about this information. I understand what is being proposed and the procedures in which I will be involved have been explained to me.

I understand that my involvement in this study, and particular data from this research, will remain strictly confidential. Only the researcher(s) involved in the study will have access to identifying data. It has been explained to me what will happen once the research study has been completed.

I hereby freely and fully consent to participate in the study, which has been fully explained to me. Having given this consent I understand that I have the right to withdraw from the study at any time without disadvantage to myself and without being obliged to give any reason. I also understand that should I withdraw, the researcher reserves the right to use my anonymous data in the write-up of the study and in any further analysis that may be conducted by the researcher.

Participant's Name (BLOCK CAPITALS)

.....

Participant's Signature

.....

Researcher's Name (BLOCK CAPITALS)

.....

Researcher's Signature

.....

## **Appendix G: Focus Group Schedule**

*Welcome, introductions, brief reminder of the purpose of the focus group*  
*Practicalities*

- Remind about consent; confidentiality and right to withdraw
  - Ensure completed consent form
- Timing of the session

#### *Ground rules*

- Confidentiality
- Respecting others/different views/experiences
- Mobiles off

#### *Recording*

- Just a reminder that session will be recorded
- Reminder that I will be transcribing the recordings myself and all personally identifiable information including names will be changed when I do this.
- Ask you to bear in mind recording when you speak

#### *My role in the session*

- Keen to hear your words and what you think is important/relevant
- Very important there are no “right or wrongs” here in terms of what to talk about.
- I have some questions/prompts that I will put to the group to guide discussion but the aim is to capture your own thoughts and experiences.

#### *Getting upset*

- [Name of member of charity] is here if you are finding the discussion particularly upsetting. If you feel the need to leave the session at any time that's fine, they may go with you just to make sure you are ok.

#### *Introductions before we begin*

- Would it be helpful to go around the group to say our names?
- Reminder names will be changed
- Not obliged to say your name

*Any questions before we start recording and begin the session?*

### **[RECORD ON BOTH RECORDERS]**

### **Questions and themes**

As a broad starting point to get the ball rolling, could someone start us off by telling a bit about what your experience of grief have been?

- *Grief*



- What is your experience of grief?
- What has 'grief' felt like to you?
- How would you describe 'grief'?
- How has this impacted on you/your life?
- How have others responded to your grief
- *Experiences of loss*
  - Can you tell me a little about what your experience has been?
  - How has your loss impacted you/your life?
  - What has 'loss' felt like to you?
- *Experience of death*
  - What was your initial response to the death? (How did that change?)
  - What did the experience feel like? What was it like?
  - How did you think about it? How did you behave?
  - How did other people respond/behave?
- *Death/bereavement due to cancer*
  - How did the fact that (your partner) died from cancer impact on you?
  - What did it mean to you that (your partner) died from cancer?
  - How did others respond to hearing that it was caused by cancer?
- *Talking about the death with others*
  - Did you talk about it? (Did you want to/not want to?)
  - Did others pick up on/act on your wishes?
  - How was it spoken about?
  - What was the impact of these conversations on you?
- *How others have responded to your bereavement?*
  - How have other people responded to your loss/to you since the death?
  - How has [bereavement] been communicated/spoken about?
    - Within the family?
    - Friends/colleagues/others?
    - Professionals?
  - How have your relationships/friendships been affected?
    - What has that felt like?
    - How have you thought about that/What did you do?
  - How has that affected your role/how you function within the family/with friends/at work?

- *Have you read anything about bereavement or been given any information? Or seen anything on TV etc.?*
  - If so, what?
  - What impact did this have you?
- *What has been helpful or supportive versus unhelpful?*
- *Impact of bereavement on identity*
  - Has your experience of loss/grief changed how you think about yourself or your sense of identity?
    - In what way?
    - How did you used to feel/be?

### **Last 10 minutes:**

We've covered a lot of very interesting ideas – would anyone like to say something that they feel haven't been said before we finish?

### **[TURN OFF RECORDERS]**

### **Grounding before finish**

- Reached the end of the session.
- Summary of topics today.
- Reminder of rationale for research and how contributions have helped with this
- Thank-you for involvement in this

### **Will provide feedback on my findings**

### **Debrief**

We have covered some difficult and emotional topics today, which may leave you feeling a little emotionally heavy. [Name of member of charity] is here if you have any questions or would like information about support from the charity. I also have some information about other services you can contact if you feel you need further support after today's session.

Please contact me with any queries or concerns.

### **Appendix H: Transcription Conventions**

(.) indicates a pause.

(...) indicates that part of the transcript has been omitted.

**[inaudible]** inaudible section of recording.

**[text]** used to provide descriptive information including laughter, or when names or identifying information had been removed for reasons of confidentiality

< > signifies an interjection.

\_\_\_\_\_ An underscore was used to signify words that were noticeably emphasised

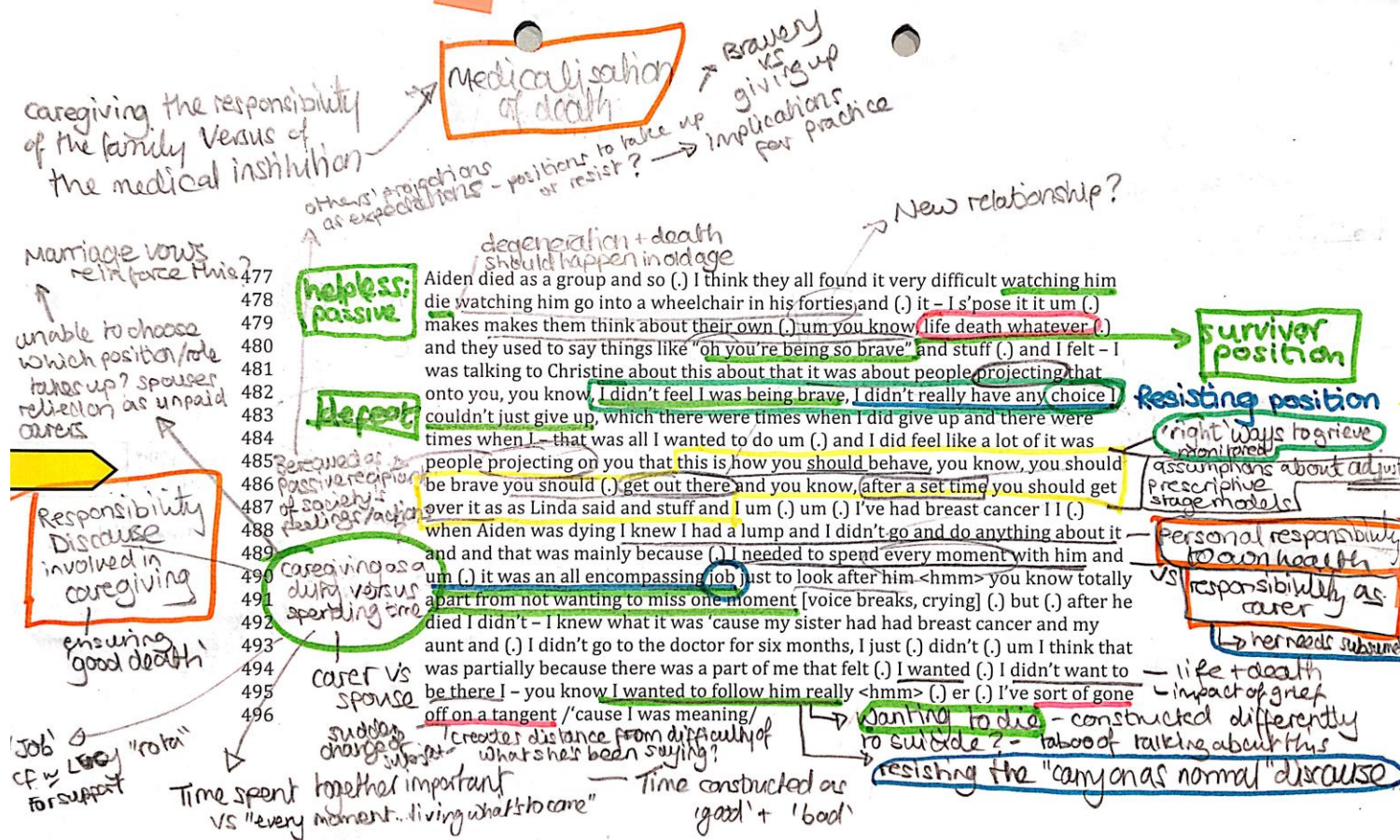
*/text/* utterances that were spoken at the same time as another speaker were denoted by the use of forward slashes

Sounds such as “mm” and “er”, colloquialisms, abbreviations, stutters and half-said words have all been transcribed phonetically..

Punctuation was added to facilitate reading.

Informed by Malson (1998, p. xv)

## Appendix I: Example from Transcript



## **Appendix J: Foucauldian ‘Tool Box’ Approach**

A brief outline of some of the key Foucauldian concepts that were used throughout this study are provided below.

- Surveillance: this relates to the notion of the panopticon prison, in which prisoners are subject to continual observation from but the prison guard, who is all-seeing yet anonymous. Individuals internalise this process and engage in self-surveillance (Foucault, 1977).
- Normalisation: Method of measuring population by imposing homogeneity through which behaviour is observed judged and rewarded in accordance with conformity. ‘Normality’ is achieved through self-improvement and deviation from the norm engenders abnormality and associated stigma.
- Power/ knowledge: Foucault conceived power being inextricably linked; knowledge is the result of the exercise of power and power serves as a function of knowledge. (Foucault, 1978)
- Technologies of Power: Represent the institutional practices and techniques, which enable surveillance and social control from a distance. (Foucault, 1982).
- Technologies of the Self: Represent the practices and techniques through which individuals engage in via self-examination and self-regulation so as to shape their behaviour in society and reproduce the operation of power (Foucault, 1988).

## **Appendix K: Reflective Diary Extracts**

### Following Focus Groups 1 and 2:

It was a very humbling experience to facilitate today's groups especially hearing some of the experiences people had gone through during the cancer and in the difficult unsupportive interactions they had had since their partner died. It's amazing to see a group of strangers speaking so openly with one another as though they have known each other for years and offering genuine empathy and support in response to hearing their story – which was in such contrast to the silenced and shut-down interactions they described with other people. Even though the groups were so different, both carried a sense of connection that I felt really privileged to be part of.

It's also really interesting to think about how non-verbal communication (like nodding and connecting via eye contact) was used to convey listening and empathy in the discussion and how much I relied on this more than I would in other contexts so as to avoid disrupting the trajectory of conversations by speaking. It was valuable collecting the data from the group rather than carrying out one-to-one interviews because I was able to observe how people used one another to explain and make sense of their experiences, which made me think of social constructionism and how experience is co-constructed rather than generated within the individual.

### Following Focus Group 3:

This group was again very different to the other two. I had an interesting interaction before the group began and the first participant had arrived early because she started asking me about the research and why I had chosen to do it. She initially came across as so calm and 'ok' in herself but as soon as I gave some of my rationale she burst into tears and said how newly bereaved she was and that this was the first time she had been in an environment where it was spoken about so openly. I was really struck by the contrast with how she came across initially and how vulnerable she appeared when she revealed her

emotions. Throughout the session she often burst into tears whilst telling her story and I recall feeling slightly worried as to whether I should be doing anything to ensure she was ok, but actually, despite her considerable distress, she later said to me at the end that she had found it really helpful to speak about her experiences and hear that others had experienced similar struggles. I think it's interesting that the amount she was crying made me think she might be 'too' distressed to take part and how this links to some of the dominant assumptions within society about crying and expression of emotion.

### **During Analysis**

I feel really overwhelmed by how much data I have across the three focus groups and am concerned that I won't have the space in the write up to represent participants varying contributions.

By taking an FDA approach I'm bringing a certain type of critical lens – wondering how my participants would respond to some of my interpretations and whether this could be received as invalidating – like naming positions as 'passive' or some of the thoughts I've had about gender distinctions.