

Bereaved Parents' Narratives of Their Journeys Through Grief

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Abstract

Rationale and aims: The death of a child is understood to be a particularly devastating form of loss for parents, and there remains a need to further understand bereaved parents' experiences in order to inform the support offered to them. Empirical studies that explore bereaved parents' experiences of grief over time in a UK context using narrative inquiry are scarce. The study aims to explore the stories bereaved parents tell about adjusting to living life following bereavement, in order to further understand bereaved parents' experiences of grief over time and inform the interventions offered to support them. **Methodology:** A qualitative design, specifically a narrative inquiry, was utilised to explore the accounts of eight bereaved parents, who self-identified as having 'gradually adjusted' to living life without their child. Recruitment was facilitated by a peer-support charity for bereaved parents, and a self-selecting sampling method was used. Data was gathered via semi-structured interviews, which were recorded, transcribed and analysed individually and then collectively using thematic, structural and performance narrative analysis methodologies. **Findings:** Participants described the loss of their child as an earth-shattering disaster, and told stories of surviving and adapting to a world irrevocably altered by loss. Participants described initial grief which felt non-survivable, and later grief which felt never-ending and poorly understood by others, with the exception of other bereaved parents. **Implications:** This research provides new insight into the challenges faced by bereaved parents, particularly in their later grief, which has implications regarding the timing of interventions for bereaved parents. The study findings also highlight the need for professionals to be informed regarding the never-ending nature of parental grief, and for bereaved parents to have opportunities to connect with one another.

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Chapter One: Introduction

1.1 Chapter Overview

This chapter introduces the research by stating the researcher's epistemological and personal position, before defining key terms and presenting an overview of relevant literature.

1.2 Positioning the Research

This research focuses on the stories of parents who have experienced the death of their child, and was conducted in the UK between September 2021 and June 2023.

1.2.1 Ontological and Epistemological Positions

Ontology refers to one's view of the nature of reality, whilst epistemology refers to one's view of the nature of knowledge, or what can be known about said reality (Marsh et al., 2017). A researcher's ontological and epistemological position will influence both their choice of research methodology and the way research findings are presented (Scotland, 2012).

This research adopts a critical realist ontology. Critical realism (Bhaskar, 1978) assumes that there is a reality that exists independently of what can be observed and perceived by humans. In keeping with this position, this study assumes that bereavement is a real experience, although the way it is experienced and perceived will vary between individuals.

With regards to epistemology, this research takes a social constructionist position. Burr (2015) explains that this approach considers all knowledge as sustained by social processes and interactions, shaped by historical and cultural

context. This position is fitting for the current research which is concerned with knowledge in the form of stories, with the assumption that stories are co-constructed between speaker and listener, and are influenced by interpersonal, social and cultural relations (Esin et al., 2013).

1.2.2 Personal Position

I am a trainee clinical psychologist in the final year of my doctoral training. Both prior to and during training, I have predominantly worked in child and adolescent mental health services, and as a result have developed an interest in child and family wellbeing. Over the course of training, I have developed a particular interest in parental mental health, which may have drawn me to the topic of this thesis. Throughout this research I considered my position as a mental health clinician with experience of working therapeutically with parents, and how this may have affected my interactions with participants and my interpretations of their experiences (see reflexivity processes outlined in Chapter 3). Additionally, I was drawn to this project after learning about the work of a charity that supports bereaved parents. I was interested in conducting my thesis alongside a charity, as I am passionate about psychologists working with third sector services, having volunteered with charities in the past and currently completing my final year placement in the charity sector. This research was developed and delivered alongside the parental bereavement charity, and again I engaged in reflexivity processes (see Chapter 3) to consider how my feelings of wanting to support the charity may have impacted the research at all stages.

I will be approaching this research as an outsider researcher, as I am neither a parent nor someone with significant experience of bereavement. Dwyer and Buckle (2009) discuss issues related to being an outsider researcher when conducting

research with bereaved parents, as highlighted by one participant: “*It’s different if you’re a member of the club... you talk differently to people who have lost somebody*” (p.57). However, the authors later report that despite these issues, they were able to gather meaningful interview data and that parents gave positive feedback about their participation in the research. It has also been suggested that outsider status may help researchers to maintain an open-minded and critical view of data (Tinker & Armstrong, 2008). It is recommended that outsider researchers consider the impact their identity may have on research through processes of reflexivity (Joseph et al., 2021), discussed further in Chapter 3.

1.2.3 Positioning Through Language

As highlighted, this research will require me to consider how stories are co-constructed between myself and the research participants. At other points in this thesis, I will strive to maintain a more objective and academic stance. In order to accommodate both of these positions, I have chosen to write in both the first person (suggestive of a personal writing style) and the third person (suggestive of an academic writing style), as appropriate.

1.3 Defining Key Terms

The terms *bereavement* and *grief* are often used interchangeably or inconsistently in literature (Zisook & Shear, 2009), and as such there is a need to define them for the purposes of this research.

Bereavement can be defined as the “situation one faces after having lost an important person via death” whilst grief can be defined as “the primarily emotional/affective process of reacting to the loss of a loved one through death” with a focus on “the internal, intrapsychic process of the individual” (National Cancer Institute, 2022,

Definitions of Terms section). This research adopts these definitions when discussing parental bereavement and grief (respectively, the situation of a parent's child dying, and a parent's subjective experience or response to this).

For the purposes of this research, parental bereavement refers to a parent's child dying at any age, due to any circumstances. This includes stillbirths, but not miscarriage or pregnancy loss¹, in line with research that suggests that stillbirth death is associated with higher levels of parental grief symptoms than miscarriage, and leads to similar grief responses to other types of child and infant loss (Cuisinier et al., 1993; Das et al., 2021; Ryninks et al., 2022; Wonch Hill et al., 2017).

1.4 Background Literature

1.4.1 Theoretical Models of Grief

For over a century, theorists have attempted to conceptualise grief. Freud (1917) described grief as the loss of a personal attachment, which leaves an individual in either a state of mourning - a finite state of seeking and then relinquishing the lost attachment, or melancholia - a pathological state of depression where the loss remains unprocessed in the unconscious. Although this theory has been largely influential it has been criticised over the years, particularly due to its emphasis on severing attachments with the dead (Klass et al., 1996) which Freud himself contradicted in later writing by acknowledging the never-ending nature of grief (Clewell, 2004).

Bowlby (1961) also conceptualised grief as the loss of an attachment, describing the process as a natural response to separation. Developing this theory

¹ In the UK, a death is considered a stillbirth if a baby is born dead after 24-weeks' gestation, and foetal deaths prior to 24-weeks' gestation are considered miscarriages (NHS, 2021).

further, Bowlby and Parkes (1970) proposed four phases of grief (Numbing, Yearning, Disorganisation and Reorganisation), with the final phase involving acceptance of the lost attachment. Similarly, the 5-staged model of grief (Kübler-Ross, 1969) suggests that individuals move through a sequence of emotions (Denial, Anger, Bargaining and Depression) before reaching a final "Acceptance" stage, where they are able to acknowledge the reality of their loss and re-engage with life. Despite remaining popular conceptualisations of grief, staged models have been largely criticised in recent years due to their portrayal of grief as a predictable, linear experience despite a lack of supporting evidence, which may be harmful to bereaved people who do not relate to such a trajectory (Avis et al., 2021; Stroebe et al., 2017).

Other theorists (Rando, 1993; Worden, 1991) have conceptualised grief as a series of 'tasks' that bereaved people complete in order to adjust to bereavement, such as reacting emotionally to the loss, acknowledging its reality and investing in new life. These models aim to empower bereaved people to take an active role in their own recovery, and deviate from staged models in that tasks can be completed in any order (Riely, 2003; Sprang & McNeil, 1995). However, Bonanno and Kaltman (2001) criticise task-oriented models of grief, as they are "rife with assumptions about what grieving should be" and "there is no evidence to support traditional assumptions that it is necessary to express the pain of loss, ... work through the thoughts and memories associated with loss, or... relinquish attachments to the deceased" (p.709).

Several non-staged alternative models of grief have been put forward. Klass et al. (1996) propose a "continuing bonds" theory of grief, which emphasises the importance of an ongoing relationship with the deceased, challenging ideas that individuals must sever ties or 'move on' from bereaved relationships in order to work

through grief. There may be a need to clarify what are considered “adaptive” or “maladaptive” expressions of continuing bonds (Field, 2006) as authors argue that some individuals may benefit from a “loosening of the bond” in order to “rebuild their lives more independently of the deceased” (Stroebe, 2010, p.266). Root & Exline (2014) highlight that continuing bonds may be considered “maladaptive” if a bereaved individual perceives them as intrusive or associated with negative affect, for example hallucinations and illusions of the deceased may particularly be associated with increased distress for bereaved individuals (Field et al., 2013; Sekowski, 2021). It has been suggested that the adaptiveness of continuing bonds might be affected by an individual’s attachment style as well as their relationship type with the deceased (Field et al., 2005; Stroebe et al., 2010). Furthermore, Klass (2006) highlighted that there may be cultural differences in how relationships are maintained with the deceased, and recommended that continuing bonds should always be considered within a social, cultural and political context.

Tonkin (1996) proposed a model of “growing around grief”, suggesting that whilst grief is life-long and a bereaved individual may continue to be immersed in their loss at times, at other times they can grow and experience life outside of their loss. This model suggests that an individual’s grief does not shrink or disappear, but rather, their life outside of grief grows bigger over time. Another model of grief is the “dual process model” (Stroebe & Schut, 1999), which suggests that bereaved individuals oscillate between a loss-oriented state (i.e. intrusion of grief) and a restoration-oriented state (i.e. distraction or attending to life changes) of coping. Both these models suggest a non-linear process in grief, where an individual may respond to bereavement differently at certain times and in a non-sequential way. These models allow for multiple ways of adjusting to loss, however a limitation of this might

be that it is unclear how and whether individuals should take agency in facilitating their own grief or whether they remain passive in these processes (Carr, 2010).

Neimeyer (2001a) proposes a model of “meaning reconstruction” in bereavement. This model views grieving as “a process of reconstructing a world of meaning that has been challenged by loss” (Neimeyer et al., 2010, p.73). According to this model, individuals reconstruct meaning in response to loss in three ways: sense-making (questioning and making sense of bereavement), benefit finding (identifying learnings or benefits born out of loss) and identity change (i.e. post-traumatic growth²). This model has implications for bereavement interventions and argues that therapy should support individuals to engage in these meaning-making processes (Neimeyer, 2001b). Neimeyer and other authors have also proposed a narrative approach to death and grief which acknowledges that a relationship between the living and the deceased continues, particularly emphasising that the deceased can continue to have important influence on bereaved individuals' lives (Hedtke & Winslade, 2004; Neimeyer et al., 2014a; White, 1988). This again challenges the idea of severing attachments with the deceased, and aligns with a continuing bonds conceptualisation of grief (Klass et al., 1996).

There is some literature that suggests that a ‘one-size-fits-all’ model of grief is not justified and that grief should be formulated uniquely for each bereaved individual (Hall, 2014). This is particularly important given that grief responses have been shown to vary depending on an individual's cultural and social context (Silverman et al., 2021; Stroebe & Schut, 1998). However, much literature continues to conceptualise grief as a relatively predictable experience, and can medicalise grief

² Post-traumatic growth is a term developed by Tedeschi et al. (1998) to describe positive personal change in individuals following adverse experiences.

into 'normal' vs. 'pathological'³ experiences, largely based on research with white Western people (Breen & O'Connor, 2007; Davies, 2004). There is therefore a need to understand grief processes as experienced by bereaved people and to consider these experiences within their own unique contexts (Breen & O'Connor, 2007).

1.4.2 Influence of Culture on Grief

Walter (2010) writes: "All groups, from families to entire societies, have a culture: a way of doing things and a set of norms about how things ought to be done. One of these things is grief" (p.5). Grief has been described as an essentially universal experience (Stroebe & Schut, 1998), however it is acknowledged that how an individual experiences and copes with grief will be influenced by their cultural context (Smid et al., 2018). Different cultural groups will have different norms and expectations regarding mourning rituals and the length of the mourning period, as well as what is deemed acceptable or 'normal' expression of emotions and grief (Rosenblatt, 2017).

Western societies can be described as "death-denying" (Kübler-Ross, 1975) and it is possible that this attitude has evolved over time due to a decreased prevalence of religion as well as high expectations regarding health and life-span in the Western world (Ariès, 2000). Aging, dying and bereaved individuals are at risk of being marginalised in Western society, due to the fact that they serve as a reminder of human mortality, in a culture which values youth and vitality (Harris, 2010). Western cultures tend to see grief as a journey towards closure and re-establishing self-sufficiency, in line with individualism (Walter, 2010). It is also argued that Western society's capitalistic nature, which values productivity, puts pressure on

³ For example, the DSM-5-TR (diagnostic and statistical manual of mental disorders, 5th edition, text revision) lists "prolonged grief disorder" as a diagnosis (American Psychiatric Association, 2022).

bereaved people to return to functionality within an expected timeframe (Harris, 2010).

In contrast, in many collectivist cultures death is not regarded as the end of life, but rather as a marker of life continuing in a different realm (Ekore & Lanre-Abass, 2016; Ho & Brotherson, 2007). Collectivist societies often place emphasis on continuing relationships with and carrying out responsibilities for the dead (Walter, 2010), such as by engaging in ongoing cultural rituals to maintain a connection with the deceased, and trying to live a life which honours one's ancestors (Hsu et al., 2009; Klass, 1996). These understandings of bereavement are often intertwined with spiritual and religious beliefs (Walter, 2010).

Cultural expectations and norms related to grief can create social pressure for bereaved individuals who feel the need to conform to them (Neimeyer et al., 2014b), and these individuals are at risk of feeling misunderstood and marginalised by society (Harris, 2010). Furthermore, some bereaved people may experience disenfranchised grief⁴. This can occur due to societal expectations regarding types of loss, for example, the death of elderly people can often be minimised in societies (Moss & Moss, 2003) as can stillbirth and early perinatal death (Lang et al., 2011; Pollock et al., 2020). Certain causes of death may result in disenfranchisement, for example when individuals die of AIDS, suicide or substance misuse (Corr, 1999; Doka, 1999; Valentine et al., 2016), with some cultures believing that such deaths are shameful or associated with negative consequences in the afterlife (Čepulienė et al., 2021; Nzioka, 2000). In some cultures, stillbirth or the death of a child can be considered a sign of punishment for parental wrongdoing, leading to the blame and

⁴ "Disenfranchised grief" is a term which describes grief that is not acknowledged or validated by society (Doka, 2008).

stigmatisation of bereaved parents (Ayebare et al., 2021; Fu et al., 2020; Pollock et al., 2020).

Disenfranchisement can also occur when an individual expresses their grief in a way that is deemed inappropriate within their culture or society. For example, many cultures have expectations regarding acceptable emotional expression in men and women, which can mean that men are expected to remain stoic in response to bereavement (Harris, 2010; Martin & Doka, 2000). Spiritual beliefs can also influence norms regarding grief expression, with some cultures believing that high or prolonged expression of distress in response to grief can have negative spiritual repercussions (Stroebe & Schut, 1998; Wikan, 1988), whilst in other cultures mourning rituals involve expressing high levels of emotion (Gamliel, 2007; Kilonzo & Hogan, 1999).

It is important to note that individuals who belong to a cultural group that is not the dominant culture of where they live may have to contend with multiple societal and cultural expectations regarding their grief (Granek & Peleg-Sagy, 2017; Maddrell et al., 2022). In addition, cultural groups are not homogenous, and individual factors such as gender, generation and class will also influence someone's assumptions about grief (Walter, 2010). It is therefore recommended that practitioners supporting bereaved people undertake a person-centred approach, making efforts to learn and listen about an individual's cultural understanding of bereavement and grief, whilst being mindful of their own assumptions regarding this (Smid, 2018; Walter, 2010).

1.4.3 Parental Bereavement

1.4.3.1 Grief Length and Intensity. Research suggests that parental bereavement is unique from other kinds of loss and is associated with a more intense and prolonged form of grief (Rando, 1985; Rosof, 1995; Sanders, 1980). It has been suggested that this is because the death of a parent's child goes against the natural order of life, and "attacks the very premise of all that being a parent incorporates" (Goldstein, 2018, p.148). There is much literature which suggests that parental grief is lifelong (Arnold & Gemma, 2008; Malkinson & Bar-tur, 2000; Weed, 2007) and is associated with a number of long-term effects (De Vries et al., 1997; Rogers et al., 2008; Song et al., 2010).

1.4.3.2 Impact on Physical Health. Several studies have reported that compared to non-bereaved controls, bereaved parents are at increased long-term risk of developing illnesses including cancer and heart disease (Hendrickson, 2009; Huang et al., 2013; Wei et al., 2021). It is possible that these effects are caused by adverse lifestyle factors such as smoking, alcohol use or reduced physical activity (Li et al., 2002; Stroebe et al., 2007). There is some evidence that bereaved parents are at increased risk of mortality compared to general populations (Cohen-Mansfield et al., 2013; Li et al., 2003; Rostila et al., 2012) although other research has not found such effects (Kvikstad & Vatten, 1996; Levav et al., 1988). Studies that have used self-report measures have found that bereaved parents tend to rate their own physical health as poorer than controls (De Vries et al., 1997; Song et al., 2010; Zheng et al., 2017).

1.4.3.3 Impact on Mental Health. Several studies have found that bereaved parents self-report long-term poorer mental health than controls (Liu et al., 2013; Omerov et al., 2013; Rogers et al., 2008). Research suggests bereaved parents are

particularly at risk of long-term depression (Huo et al., 2022; Lykke et al., 2019; Pohlkamp et al., 2019) and are more likely than controls to use psychotropic medications (Hovén et al., 2023; Rostila et al., 2018). Some studies have found that bereaved parents are at increased risk of completing suicide (Li et al., 2003; Qin & Mortensen, 2003). Other studies have found that over time, bereaved parents' self-reported mental health returns to a level similar to controls (Floyd et al., 2013; Kreicbergs et al., 2004).

1.4.3.4 Impact on Marital Relationships. Literature suggests that marital relationships can be strained by the death of a child for a number of possible reasons, including incongruence in grief responses, communication styles and ways of coping (Albuquerque et al., 2016; Buchanan, 2023). Some longitudinal studies have found that divorce rates are increased amongst bereaved parents (Lyngstad, 2013; Najman et al., 1993), however the evidence regarding this is inconclusive and some parents have reported that their marital relationship has improved or strengthened post-bereavement (Murphy et al., 2003; Oliver, 1999; Schwab, 1998). It is suggested that the impact of grief on the marital relationship may be influenced by a number of individual and dyadic factors such as interdependence, empathy and willingness to talk about emotions (Albuquerque et al., 2019; Dyregrov et al., 2020).

1.4.3.5 Impact on Relationships with Surviving Children. When a child dies, it has a profound impact on all members of a family (Bowlby-West, 1983). Crehan (2004) suggests that surviving children of bereaved parents may have to contend with taking on the role of a "replacement child", or might experience their parents as distant, over-protective or blaming towards them. Some research has found that bereaved parents report difficulties in parenting their surviving children due to feeling consumed by grief (Barrera et al., 2007) or experiencing heightened

anxiety about facing the death of another child (Rosenblatt, 2000). In contrast, other research has found that bereaved parents report no change or even improvement in their relationship with their surviving children post-loss (Arnold et al., 2005; Foster et al., 2012). Qualitative research with bereaved parents has described a process whereby parents have to navigate engaging with their living children whilst grieving and remaining connected to their deceased child (Buckle & Fleming, 2011; Shankar et al., 2017).

1.4.3.6 Gender Differences. Research has generally found that bereaved mothers tend to report a more intense grief response than bereaved fathers (Keesee et al., 2008; Sidmore, 2000; Wing et al., 2001). There is evidence that compared to bereaved fathers, bereaved mothers are more likely to experience mental health problems including depression and posttraumatic stress (Baumann et al., 2022; Chen et al., 2021; Murphy et al., 1999; Vance et al., 1995), as well as feelings of guilt and self-blame (Schwab, 1996; Wing et al., 2001), and physical health problems (Huang et al., 2013; Li et al., 2002, 2003).

There is particularly strong evidence that grief responses between men and women differ in the case of stillbirth or perinatal death (Cacciatore et al., 2008; Jones et al., 2019; McGreal et al., 1997). Reviews of fathers' experiences of such deaths have concluded that fathers tend to adopt a role of protecting and supporting their female partners (Badenhorst et al., 2006), and may "suppress" their own grief responses (Burden et al., 2016). Research has found that bereaved fathers can feel "ignored and unacknowledged as a legitimate grieving parent" (Lang et al., 2011, p.191), and may have limited "opportunities to grieve" (Campbell-Jackson et al., 2014, p.10). Bonnette and Broom (2012) suggested that men's experiences of stillbirth were influenced by gender stereotypes, in that men reported a desire to fulfil

the male 'role' of remaining strong and stoic, whilst also struggling with intense emotions and finding it difficult when others did not acknowledge their loss.

Research has explored differences in male and female coping responses to the death of a child. A review of paternal grief (McNeil et al., 2021) found that bereaved fathers often used distraction to cope, such as immersion in work or practical projects, whilst studies have found that bereaved mothers are more likely to engage in emotion-focused coping such as crying, and talking or writing about the loss (Christiansen et al., 2014; Kavanaugh, 1997; Schwab, 1990). There is some evidence that bereaved mothers are more likely to seek support from others in managing their grief (Carroll & Shaefer, 1994; McNeil et al., 2021).

It should be noted that some research has not found gender differences in bereaved parents' grief reactions (Delgado et al., 2023; Song et al., 2010; Wing et al., 2001) and it is suggested that a range of individual, environmental and situational variables may influence parents' responses to bereavement (Keesee et al., 2008; Titlestad et al., 2022; Wijngaards-de Meij et al., 2005).

1.4.3.7 Risk and Protective Factors. Research has explored factors that may increase or decrease the risk of bereaved parents experiencing more severe or prolonged grief. Risk factors identified in research include financial pressure or having a lower household income (McCarthy et al., 2010; Zhang et al., 2020; Zhao et al., 2022; Zhou et al., 2020), physical health problems (Xiu et al., 2016; Zhang et al., 2020; Zhou et al., 2020), violent death of a child (Keesee et al., 2008; Wijngaards-de Meij et al., 2005; Zhao et al., 2022) and perceived stigma (Feigelman, Gorman, et al., 2009; Zhao et al., 2022). There is some evidence to suggest that in Western societies, bereaved parents from racially minoritised backgrounds report more severe grief symptoms (Suttle et al., 2022; Youngblut et al., 2013). Factors

associated with reduced risk of severe or prolonged grief include having surviving children (Flach et al., 2022; Kersting & Wagner, 2012; Meert et al., 2011; Wijngaards-de Meij et al., 2005) and higher perceived social support (Flach et al., 2022; Kersting & Wagner, 2012; Riley et al., 2007; Xu et al., 2017).

Other research has found that individual factors such as personality and cognitive styles may influence parents' grief trajectories. Research has found that parents with traits of neuroticism (Robinson & Marwit, 2006) and cynicism (Xiu et al., 2016) may be at risk of more prolonged grief, whereas traits of resilience (Vegsund et al., 2019) and optimism (Riley et al., 2007) may be protective in grief. Wijngaards-de Meij et al. (2007) found that parents with an insecure attachment style were more likely to experience severe grief symptoms. In a study by Keesee et al. (2008), sense-making was named as the most significant predictor of grief severity, with parents who reported having made little or no sense of their child's death reporting more severe grief symptoms.

1.4.3.8 Post-Traumatic Growth. Studies have shown that post-traumatic growth (i.e. positive personal changes that occur as a result of loss – Calhoun & Tedeschi, 2001) is often evident in bereaved parents (Engelkemeyer & Marwit, 2008; Waugh et al., 2018), and this is more likely the more time has passed since their loss (Feigelman, Jordan, et al., 2009; Polatinsky & Esprey, 2000). Post-traumatic growth has been found to have a negative relationship with grief intensity and mental health problems in bereaved parents (Engelkemeyer & Marwit, 2008; Feigelman, Jordan, et al., 2009). There is some evidence that post-traumatic growth is more prevalent in bereaved mothers than fathers (Albuquerque et al., 2018; Büchi et al., 2007; Jenewein et al., 2008).

Some research has found a positive relationship between social support and post-traumatic growth (Parappully et al., 2002; Riley et al., 2007) and support from other bereaved parents has been named as particularly helpful (Feigelman, Jordan, et al., 2009; Parappully et al., 2002; Reilly et al., 2008). Jenewein et al. (2008) found that following bereavement, mothers reported more valued and enhanced relationships with others, and other papers have described bereaved parents feeling more compassionate and compelled to help others (Bogensperger & Lueger-Schuster, 2014; Brabant et al., 1997; Moore et al., 2015; Parappully et al., 2002). Some literature names an association between post-traumatic growth and a continued bond with the deceased child (Albuquerque et al., 2018; Parappully et al., 2002).

Other studies have found that bereaved parents report changed values and priorities (Bogensperger & Lueger-Schuster, 2014; Brabant et al., 1997; Büchi et al., 2007) or an increased appreciation for life (Bogensperger & Lueger-Schuster, 2014; Moore et al., 2015) post-bereavement. A relationship between finding meaning in or making sense of experiences and post-traumatic growth is suggested (Bogensperger & Lueger-Schuster, 2014; Parappully et al., 2002). Some papers propose that spirituality facilitates post-traumatic growth (Khursheed & Shahnawaz, 2020; Parappully et al., 2002) whereas others describe parents feeling more spiritual as a result of their loss (Brabant et al., 1997; Moore et al., 2015).

Several papers highlight that it is difficult to establish cause and effect between certain variables and post-traumatic growth (Feigelman, Jordan, et al., 2009; Moore et al., 2015; Waugh et al., 2018). In other words, it is difficult to distinguish whether individuals who possess certain qualities or engage in certain ways of coping are more likely to experience post-traumatic growth, or whether post-

traumatic growth enables individuals to develop such qualities and coping resources. Waugh et al. (2018) conclude their review of this topic by stating that there is a need for more in-depth qualitative research to explore how bereaved parents achieve personal growth over time.

1.4.4 Summary

In summary, several theorists have attempted to conceptualise the grief process, and in recent decades there has been a movement away from staged models towards a more individual and non-linear understanding of grief. There is acknowledgement in the literature that grief is influenced by a number of factors including an individual's culture and gender, as well as other risk and protective factors. Parental bereavement is generally considered to be a particularly devastating form of loss, and is associated with several negative impacts although also with post-traumatic growth. There is a need to further understand parental bereavement as experienced by parents themselves (Denhup, 2019). The next chapter makes efforts to explore what is known so far about this, as well as to position the current study in line with research gaps.

Chapter Two: Systematic Literature Review & Research Aims

2.1 Chapter Overview

This chapter outlines a systematic literature review (SLR), which was conducted in order to identify, synthesise and critically appraise empirical literature relevant to this study. The SLR aims and methodology are presented, followed by a quality evaluation of selected literature and a thematic synthesis of literature findings. The SLR is then summarised and critically reviewed, which leads to the presentation of the current study's rationale and aims.

2.2 SLR Aims

This SLR initially aimed to answer the question '*what is known about how bereaved parents experience grief?*' however, through scoping the literature, this proved to be a well-researched and reviewed area. The SLR question was therefore refined to '*what is known about how bereaved parents experience grief over time?*'. The use of the term 'over time' aimed to narrow the search to papers that either a) described a trajectory of parental grief, or b) compared data gathered from bereaved parents at two or more time points, in order to further understand parents' experiences of how their grief changes and develops.

2.3 SLR Methods

2.3.1 Search Strategy

The SLR was conducted between October 2022 and January 2023. The databases searched were Scopus, PubMed and APA PsycArticles. These databases were selected following consultation with a member of staff from the University of Hertfordshire library services, and also after conducting a scoping search of Google Scholar to gauge where research into this area tended to be published. The

reference lists of relevant papers were also reviewed for any further papers which had not been identified in the search.

2.3.2 Search Terms

Search terms were developed using the University of Hertfordshire library's search planning form (Appendix A). An initial search was conducted using broader terms, but produced a high number of results. This was discussed with my supervisory team, as well as in consultation with a University of Hertfordshire library officer. I also underwent a process of becoming better acquainted with the literature, considering the terms used in related bereavement-related reviews as well as key words that came up in papers relevant to the review. Following these processes, the search was refined and it was specified that one concept (terms related to bereavement) should appear in paper titles, and that titles should not contain terms related to other types of loss. All other terms were searched for in the title, abstract or key words of papers. Final search terms are presented in Table 1.

Table 1

*SLR Search Terms*⁵⁶

	AND	AND	AND	AND	AND NOT
<i>experience*</i>	<i>time*</i>	<i>parent*</i>	<i>child*</i>	<i>bereav*</i>	<i>hearing</i>
<i>qualitative*</i>	<i>trajector*</i>	<i>caregiver*</i>	<i>infant*</i>	<i>death</i>	<i>weight</i>
<i>interview*</i>	<i>long*</i>	<i>mother*</i>	<i>baby</i>	<i>grief</i>	<i>“parent death”</i>
<i>narrative*</i>	<i>process*</i>	<i>father*</i>	<i>babies</i>	<i>griev*</i>	<i>“death of a</i>
			<i>daughter*</i>	<i>died</i>	<i>parent”</i>
			<i>son*</i>	<i>dies</i>	<i>“bereaved</i>
			<i>neonat*</i>	<i>loss</i>	<i>child”</i>
			<i>stillb*</i>	<i>lost</i>	<i>sibling</i>
			<i>perinat*</i>		<i>pregnan*</i>

⁵ The asterisk symbol (*) is used for truncation, i.e. to search for all forms of a word that could have multiple endings such as plurals.

⁶ Search terms within each concept were separated by the word “or”.

2.3.3 Eligibility Criteria

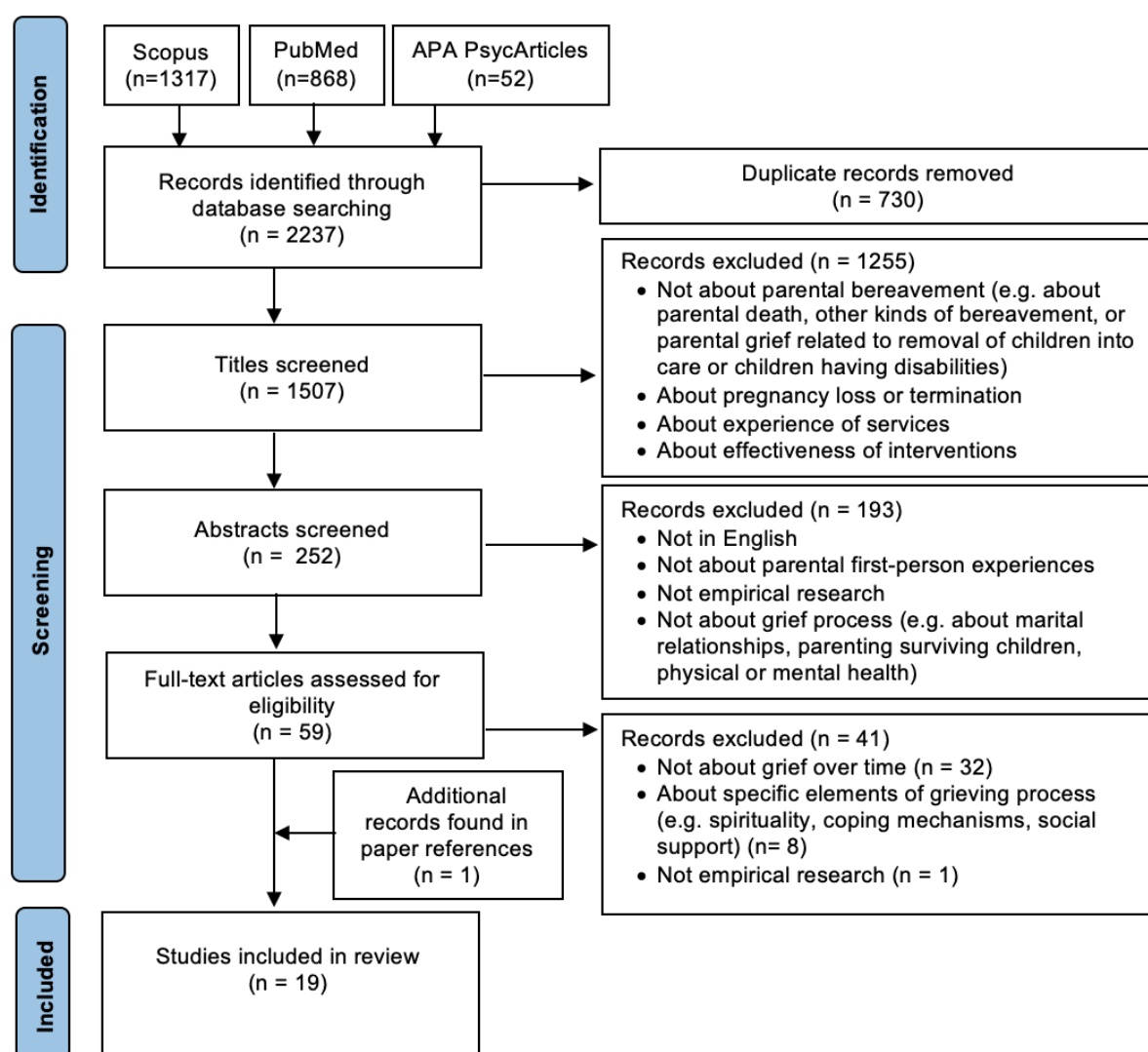
Eligibility criteria (see Table 2) were developed based on the review question and aims.

Table 2

SLR Eligibility Criteria

Inclusion Criteria	Exclusion Criteria
1. Available in English language	1. Not available in English
2. Empirical research	2. Not empirical research e.g. review or theoretical paper
3. Published in a peer-reviewed journal	3. Unpublished work or grey literature
4. Participants are parents whose child died at any age (including stillbirth)	4. Participants are not bereaved parents, or are people who have experienced pregnancy loss
5. Data includes first person accounts from bereaved parents	5. Data does not include first person accounts from bereaved parents
6. Focuses on experiences of grief over time	6. Focuses on other experiences, or experiences of grief but not over time

The initial search yielded 1507 papers, excluding duplicates. By applying the eligibility criteria, this was narrowed down to 19 papers for inclusion in the review. A PRISMA flow diagram (adapted from Page et al., 2021), presented in Figure 1, details the process of identifying papers and applying eligibility criteria.

Figure 1*PRISMA Flow Chart of SLR Search Process*

2.3.4 Synthesis Method

A thematic synthesis method described as a “tried and tested method” method for synthesising qualitative research (Thomas & Harden, 2008) was used to synthesis the SLR results. This approach was chosen given its ability to synthesise both ‘thin’ and ‘thick’ data from different qualitative studies (Noyes et al., 2022), felt to be an advantage as the papers selected for review included both ‘thin’ data (e.g. broad themes), and ‘thick’ data (e.g. rich quotes from participants). In line with this

method, the following analytic steps were taken: 1. Papers were read and re-read in full; 2. Findings sections of papers were coded in a line-by-line fashion; 3. Codes were organised into descriptive themes; 4. Analytical themes⁷ were generated, detailed in the SLR results section.

2.4 SLR Results

2.4.1 SLR Final Papers

19 papers were identified for inclusion in the review; a data extraction table (Table 3) displays these papers in chronological order and summarises their methods and key findings.

⁷ Descriptive themes are those that describe the papers' content, whilst analytical themes go 'beyond' the contents of the papers and require the researcher to make their own interpretations of data (Thomas & Harden, 2008).

Table 3*Summary of SLR Final Papers*

Author(s), Year & Title	Methods	Key Findings
<p>Kachoyeanos & Selder (1993) - Life transitions of parents at the unexpected death of a school-age and older child</p>	<p>Setting: US Participants: 27 parents (11 married couples, 5 mothers) who had lost a school-aged or older child at least 6 months ago and unexpectedly; all participants but one were described as “Caucasian” Procedure: Recruited via support group; semi-structured interviews; unspecified qualitative analysis.</p>	<p>Developed a life transition theory of parental grief, which suggests that parents must go through a transition to a new or altered reality after their child dies. Prior to this transition is a period of fog and uncertainty. The transition is achieved through various processes including increased awareness of the impact of the child’s death, finding ways to remember the child and keep them present, and re-engaging with the world.</p>
<p>Dyregrov & Dyregrov (1999) - Long-term impact of sudden infant death: A 12- to 15-year follow-up</p>	<p>Setting: Norway Participants: 25 Norwegian parents (13 mothers, 12 fathers) who had lost a child to sudden infant death syndrome between 1981 and 1984 Procedure: Follow-up to an earlier study; semi-structured interviews and questionnaires; mixed methods with unnamed qualitative analysis</p>	<p>All parents felt they were still affected by their loss 12-15 years later, although there was variance in the sample, and particularly gender differences. Mothers reported more continuing grief as well as more of a need to keep talking about their child than fathers. All parents felt the death had affected their perspective on life e.g. shifting their priorities and leaving them valuing relationships more.</p>

<p>Wheeler (2001) - Parental bereavement: The crisis of meaning</p>	<p>Setting: US Participants: 176 parents (137 mothers, 41 fathers) who had lost a child, no exclusion criteria re child's age, cause of death or time since death; 98% of participants were described as "Caucasian" Procedure: Recruited via self-help organisation newsletter; open-ended questionnaires; unspecified qualitative analysis.</p>	<p>Conceptualisation of child death as a crisis of meaning for parents, suggesting that a search for meaning is central to the process of readjustment. The process of finding meaning involved cognitive mastery as well as renewed purpose. Parents found meaning and significance in their child's life and memory, connections with others, or in positive gains resulting from the experience of bereavement.</p>
<p>Saiki-Craighill (2001) - The grieving process of Japanese mothers who have lost a child to cancer, Part I: Adjusting to life after losing a child</p>	<p>Setting: Japan Participants: 24 Japanese mothers who had lost a child to paediatric cancer Procedure: Participants all attended a 6-week support group within a year of their child dying, with follow up meetings 6 and 12 months after the sessions ended; data collected included recordings of support group meetings as well as individual interviews conducted at the time of original group sessions, and 3 months after the sessions ended; unspecified qualitative analysis.</p>	<p>Mothers experienced an initial numbing of emotions, followed by a grieving period, which included depression and difficulties dealing with the outside world. There was then a gradual movement out of depression, where mothers were able to feel more in control and recognise positives in their experience. Mothers continued to experience "waves of sadness", but these became more stable over time.</p>

<p>Malkinson & Bar-Tur (2005) - Long term bereavement processes of older parents: The three phases of grief</p>	<p>Setting: Israel Participants: 47 Israeli adults >60 years old (22 fathers, 25 mothers) who had lost an adult son in war or military service Procedure: Recruited via letters and a newsletter sent out via a peer support organisation; semi-structured interviews; content analysis.</p>	<p>An evolution in the grieving process was found, with 3 main phases of grief: acute grief, bereavement over the years, and grief in old age. A central theme was identified - the continuation of the relationship between the parent and deceased child after loss, described at a personal, inner level and at an interpersonal and social level.</p>
<p>Yamazaki (2010) - Living with stillborn babies as family members: Japanese women who experienced intrauterine fetal death after 28 weeks' gestation</p>	<p>Setting: Japan Participants: 17 Japanese women who had delivered stillborn babies at least one year ago Procedure: Recruited via support-groups; semi-structured interviews; grounded theory.</p>	<p>Women underwent a grieving process, starting from the day of foetal death, moving through a process of living with the reality of the loss and raising a child who does not exist in real life, and moving to a final stage of "always being together in a natural way". The process was not necessarily unidirectional, with some women repeating steps of the process.</p>
<p>Alam, Barrera, D'Agostino, Nicholas & Schneiderman (2012) - Bereavement experiences of mothers and fathers over time after the death of a child due to cancer</p>	<p>Setting: Canada Participants: 31 parents (18 mothers and 13 fathers) whose children had died following treatment by the haematology/ oncology unit of a children's hospital; 74% of participants were white. Procedure: Recruited via hospital records; semi-structured interviews conducted at 6- and 18-months post-death; content analysis.</p>	<p>6 major themes emerged: 1. Employment attitudes and practices; 2. Grief Expression; 3. Coping with grief and bereavement; 4. Relationship with surviving children; 5. Communication with spouse; 6. Relationship with other family members. Changes over time were noted mainly in themes 1, 2, 3 and 6, with gender differences between mothers and fathers observed and described across all themes.</p>

<p>Tan & Ketola (2013) - Bereaved mothers navigating the impact of their loss</p>	<p>Setting: California, US Participants: 19 mothers bereaved for at least a year, no exclusion criteria re age of child or cause of death. Participants identified as European American (15), Latina (3) and African American (1). Procedure: Recruited via “the researchers’ networks”, and fliers given to participants to further recruit; semi-structured interviews; grounded theory.</p>	<p>Grief journey described in 7 parts: 1. Traumatic experience; 2. Unbearable grief; 3. The world stopped; 4. Suicidal ideation and guilt; 5. Painful reminders; 6. No closure; 7. Connecting with deceased children (further divided into 3 categories – a) visualisation and conversing; b) religious beliefs, rituals and gravesites; c) mementoes).</p>
<p>Snaman, Kaye, Torres, Gibson & Baker (2016) - Parental grief following the death of a child from cancer: The ongoing odyssey</p>	<p>Setting: Tennessee, US Participants: 11 bereaved parents (9 mothers, 2 fathers) whose children had died of cancer following treatment at a children’s hospital; no exclusion criteria re time since death; 82% of participants were described as “Caucasian”. Procedure: Recruited from a group of parents who were involved with improving care at a specific hospital; focus group design; content analysis.</p>	<p>Four concepts emerged from parental narratives: 1. Description of the grief trajectory and evolution of grief over time; 2. Mechanisms of parental coping throughout the grief journey; 3. Factors that exacerbate parental grief; 4. Sources of parental support throughout the grief journey. Particularly highlights grief as evolving over time and a need to continue bonds with deceased children.</p>
<p>Ross, Kolves, Kunde & De Leo (2018) - Parents’ experiences of suicide-bereavement: A qualitative study at 6 and 12 months after loss</p>	<p>Setting: Queensland, Australia Participants: 14 parents (7 mothers, 7 fathers) bereaved by suicide; no mention of participant ethnicity Procedure: Parents identified from suicide register; semi-structured interviews at 6 and 12-months post-loss; thematic analysis.</p>	<p>Three key themes identified: 1. Searching for answers and sense making; 2. Coping strategies and support; 3. Finding meaning and purpose. Evidence of meaning making and post-traumatic growth at 12 months post-loss, but grief continued to be a fluctuating and dynamic process.</p>

Abdel Razeq & Al-Gamal (2018) - Mothers' lived experience of losing a newborn infant in Jordan

Setting: Amman, Jordan
Participants: 12 Jordanian mothers whose babies had died after being admitted to the NICU for at least 24 hours, within 12 months prior to data collection
Procedure: Recruited via mortality records at 2 hospitals; semi-structured interviews; thematic analysis.

3 major themes identified: 1. Longing and grieving, 2. The adaptive work of coping and 3. Moving forward but with a scar. Emphasis on reframing or making meaning of the loss in helping mothers move through phases.

Chen, Fu, Sha, Chan & Chow (2019) - Mothers coping with bereavement in the 2008 China Earthquake: A dual process model analysis

Setting: Sichuan, China
Participants: 6 Chinese mothers who had lost their only child in the 2008 Sichuan earthquake; children had all attended the same elementary school
Procedure: Recruited by visiting families who lived in a specific public housing project; semi-structured interviews conducted with each participant at 4 time points between 2008 and 2010; Interpretative phenomenological analysis (IPA).

Dual-process model used as a way to interpret experiences. At beginning, the mothers were immersed in loss-oriented grief work. As time progressed, mothers were able to begin focusing on restoration-oriented coping in order to face changes in life. The coping trajectory was a dynamic process with continued oscillation between loss- and restoration-oriented processes.

Dutta, Tan-Ho, Choo, Low, Chong, Ng, Ganapathy, Ho (2020) - Trauma to transformation: The lived experience of bereaved parents of children with chronic life-threatening illnesses in Singapore

Setting: Singapore
Participants: 25 Singaporean families (6 couples, 13 lone mothers, 4 lone fathers and 2 primary parental figures) who had lost a child aged 0-19 to chronic illness at least 6 months ago
Procedure: Recruited via community groups; semi-structured interviews; grounded theory.

Trauma to transformation model of parental grief developed, with 6 key themes.
1. Diagnosis and caregiving; 2. Power and control-oriented ritualization; 3. Loss and mourning; 4. Continuing bonds oriented ritualization; 5. Transformation and transcendence; 6. Post-traumatic growth oriented ritualization; 7. Holistic healthcare approach. Themes 1, 3 and 5 were described as major milestones, and themes 2, 4 and 6 as deliberate behaviours or rituals. Theme 7 describes the way these processes are impacted by the health and social care system.

Fu, Chen, Sha, Chan, Chow & Lou (2020) - Mothers' grief experiences of losing their only child in the 2008 Sichuan earthquake: A qualitative longitudinal study

Same participants and data as Chen et al. (2019); IPA.

Bereaved mother's grief evolved over 2 years. A process described whereby initially mothers experienced involuntary and triggered yearning, which decreased over time with increased voluntary yearning. Although yearning and missing ebbed over time, the mothers continued to have unresolved grief.

<p>Feigelman, Feigelman & Range (2020) - Grief and healing trajectories of drug-death-bereaved parents</p>	<p>Setting: US Participants: 11 parents (9 mothers, 2 fathers) who had lost an adult child to drug-induced death, no exclusion criteria re time since death. All participants were white. Procedure: Recruited via counsellors and support groups; semi-structured interviews; unspecified qualitative analysis.</p>	<p>Bereavement process described chronologically: 1. The death spiral; 2. The crash; 3. Initially sharing details; 4. Longer-term routine situations; 5. Memorialisation and post-traumatic growth. Highlights stigma and social isolation encountered by parents, and names openly disclosing the nature of death as an important step in healing.</p>
<p>Entilli, Ross, De Leo, Cipolletta & Kolves (2021) - Experiences of parental suicide-bereavement: A longitudinal qualitative analysis over two years</p>	<p>Setting: Queensland, Australia Participants: 11 parents (5 mothers and 6 fathers) bereaved by suicide; follow-up to Ross (2018) study with three drop-outs; no mention of participant ethnicity Procedure: Recruited via suicide register; semi-structured interviews at 6, 12- and 24-months post-loss; thematic analysis.</p>	<p>3 themes emerged: 1. Searching for answers and sense making; 2. Coping strategies and support; 3. Finding meaning and purpose At 24 months, there was a polarisation observed between parents still brooding in rumination and those who had shifted towards sense making.</p>
<p>Punaglom, Kongvattananon & Shu (2022) - Overcoming grief in Thai women experiencing perinatal death: A grounded theory study</p>	<p>Setting: North-Eastern Thailand Participants: 25 Thai women who had experienced perinatal loss 0.5-2 years ago Procedure: Unclear recruitment strategy; semi-structured interviews; grounded theory.</p>	<p>4 major processes described: 1. Perception of loss and grief; 2. Cultural cognitive adaptation; 3. Acceptance; 4. Overcoming grief. Core category of all processes was named as “cultural cognitive adaptation”, a process whereby women made sense of their experience and adjusted their cognitions, influenced by religious and spiritual beliefs, in order to overcome grief.</p>

Sterling, Muruthi, Allemdinger, Thompson-Canas, Romero & Tung (2022) - The grieving process of opioid overdose bereaved parents in Maryland

Setting: Maryland, US
Participants: 6 parents (4 mothers, 2 fathers) who had an adult child die of opioid overdose more than 2 years before the study; all participants described as "Caucasian"
Procedure: Recruited via support groups; semi-structured interviews; thematic analysis.

3 themes emerged: 1. The grieving process, which includes experiences of emotional overload, triggers and meaning making and acceptance; 2. Stigmatisation, which includes fear of disclosure and internalised stigmatisation; 3. Social support. Adaptation levels varied among participants, but all participants reported both positive and negative outcomes of their grief/ loss.

Calderwood & Alberton (2023) - Understanding the bereavement process: Voices of bereaved parents

Setting: Ontario, Canada
Participants: 20 parents (3 fathers, 17 mothers) who had lost a child at least 4 years ago, no exclusion criteria re age of child or cause of death; and 11 professionals from a range of services relevant to bereavement; all participants were white.
Procedure: Recruited via a support group, and then online advertisement; professionals recruited by sending letters to services; semi-structured interviews; unspecified qualitative analysis.

Six distinctive states identified:
1. Helplessness prior to the death; 2. Fog; 3. Turmoil; 4. Transition; 5. New beginnings; 6. Stability. Describes grief processes as non-linear, individual and never-ending. Grief symptoms reduce in intensity over time but continued bursts of grief occur. Eventually parents reach a "new normal" and a point of increased comfort and positive emotion.

The 19 papers vary in terms of circumstances of child death, with some papers specifying cause of death (including cancer, chronic illness, suicide, opioid overdose, natural disaster, war or military service, perinatal and stillbirth deaths) and others recruiting participants that had lost a child to any cause. The deceased children vary in age, ranging from stillbirth to adult deaths. In terms of time since death, some papers recruited participants in the first year of their bereavement, but still focused on how grief had developed or changed over this time period. Some papers conducted follow-ups at certain time points, others specified that participants had to be bereaved by at least a certain number of years, and some had no inclusion criteria regarding time since death. Only one paper (Malkinson & Bar-Tur, 2005) specifically recruited elderly participants.

Six studies took place in East or South East Asia (China, Japan, Thailand and Singapore), two in the Middle East (Israel and Jordan) and ten in Western countries (Australia, Canada, Norway and the US). Notably no studies from Africa or South America were identified, and only one study took place in Europe, with no studies from the UK. The papers conducted in Western contexts reported on predominantly white participant groups, suggesting a lack of cultural representation. Seven papers focused on the experiences of mothers only, and whilst the other papers explored the experiences of 'parents', only one (Ross et al., 2018) recruited an equal number of mothers and fathers, with the rest recruiting more mothers, sometimes by a significant majority. This might connect with literature suggesting that bereaved mothers are more likely to seek support or talk to others regarding their bereavement (Carroll & Shaefer, 1994; McNeil et al., 2021) as well as societal assumptions that child bereavement has a more profound impact on mothers (Jones et al., 2019; McNeil et al., 2021).

Regarding methodology, most papers used semi-structured interviews to gather data, although one used focus groups (Snaman et al., 2016) and another used open-ended questionnaires (Wheeler et al., 2001). A variety of analysis methodologies were used including grounded theory, IPA, content analysis and thematic analysis. Other papers did not specify their analysis methodology, addressed further in the next session which reviews the papers' quality.

2.4.2 Quality Evaluation

The final papers were assessed using Tracy's (2010) eight "big tent" criteria (detailed in Appendix B). This approach was chosen as it provides an in-depth structure for quality checking qualitative studies⁸ of different designs (Tracy & Hinrichs, 2017). Table 4 displays a summary of the quality checks conducted.

⁸ Although one mixed methods paper was included in the SLR only the qualitative data was extracted, meaning this quality tool was deemed still appropriate for use.

Table 4*Quality Assessment of SLR Papers*

Key	Quality Criteria (Tracy, 2010)							
	Worthy topic	Rich rigour	Sincerity	Credibility	Resonance	Significant contribution	Ethical	Meaningful coherence
✓✓ = Met to a high standard								
✓ = Met								
? = Partially met/ unclear if met								
X = Not met								
Author(s) & year published								
Kachoyeanos & Selder (1993)	✓✓	?	X	✓	✓	✓✓	?	✓
Dyregrov & Dyregrov (1999)	✓✓	?	X	?	✓	✓✓	✓	✓
Wheeler (2001)	✓✓	?	X	✓	✓	✓✓	?	✓
Saiki-Craighill (2001)	✓✓	?	?	✓	✓✓	✓✓	✓	✓
Malkinson & Bar-Tur (2005)	✓✓	✓	?	✓	✓	✓✓	✓	✓
Yamazaki (2010)	✓✓	✓	?	✓✓	✓✓	✓✓	✓	✓✓
Alam et al. (2012)	✓✓	✓	?	✓	✓	✓✓	✓	✓
Tan & Ketola (2013)	✓✓	✓	X	✓✓	✓	✓✓	✓	✓
Snaman et al. (2016)	✓✓	?	?	✓	✓	✓	✓	✓
Ross et al. (2018)	✓✓	✓	?	✓	✓	✓✓	✓✓	✓
Abdel Razeq & Al-Gamal (2018)	✓✓	✓	?	✓	✓✓	✓✓	✓✓	✓
Chen et al. (2019)	✓✓	✓	?	?	✓	✓✓	✓	✓
Dutta et al. (2020)	✓✓	✓✓	?	✓✓	✓	✓✓	✓	✓✓
Fu et al. (2020)	✓✓	✓	?	✓	✓	✓	✓	✓✓
Feigelman et al. (2020)	✓✓	?	?	✓✓	✓✓	✓✓	✓	✓
Entilli et al. (2021)	✓✓	✓	?	?	✓	✓✓	✓✓	✓
Punaglom et al. (2022)	✓✓	✓✓	?	✓✓	✓	✓✓	✓✓	✓
Sterling et al. (2022)	✓✓	✓	?	✓✓	✓	✓	✓✓	✓
Calderwood & Alberton (2023)	✓✓	?	?	✓✓	✓✓	✓	✓	✓

All papers were considered to address a worthy topic given that parental bereavement is understood to be a uniquely traumatic experience with long-lasting effects (Rando, 1986; Rogers et al., 2008; Song et al., 2010), and there remains a need to better understand this experience from parents' perspectives across different contexts (Denhup, 2019; Dias et al., 2017; McNeil et al., 2020).

With regards to rigour, seven papers (Calderwood & Alberton, 2023; Dyregrov & Dyregrov, 1999; Feigelman et al., 2020; Kachoyeanos & Selder, 1993; Saiki-Craighill, 2001; Snaman et al., 2016; Wheeler, 2001) did not explicitly state the research design or method of analysis used, meaning the appropriateness of procedures and fulfilment of this criterion could not be judged. Two papers (Dutta et al., 2020; Punaglom et al., 2022) highlighted steps taken to increase rigour, including the maintenance of an audit trail and the use of alternative data collection methods in addition to interviews such as observation, field notes and memos.

None of the papers fully met sincerity criteria, as they did not address the researcher's position in relation to the research or comment on researcher values or biases. Papers marked as partially fulfilling this criterion did so by demonstrating transparency about the methods and challenges of the research.

The majority of papers provided rich illustrative quotes from participants to evidence any findings, thus fulfilling credibility criteria. For three papers (Chen et al., 2019; Dyregrov & Dyregrov, 1999; Entilli et al., 2021) it was deemed unclear whether this criterion was met, as some conclusions were presented without supporting quotes from participants. Seven studies (Calderwood & Alberton, 2023; Dutta et al., 2020; Feigelman et al., 2020; Punaglom et al., 2022; Sterling et al., 2022; Tan & Ketola, 2013; Yamazaki, 2010) met this criterion to a high standard due to the

implementation of methods for increasing study validity, including member checking and triangulation.

With regards to resonance, the emotive nature of the research topic paired with the ubiquitous nature of loss meant that all papers were deemed to meet this criterion. Studies that were marked as meeting this criterion to a high standard were those that used illustrative quotes, client's own language, or imagery and metaphor to describe the grief process as opposed to academic language.

All studies met criteria regarding significant contribution, with the majority of papers addressing a gap in the literature with regards to the study sample, context or methodology. Four papers (Calderwood & Alberton, 2023; Fu et al., 2020; Snaman et al., 2016; Sterling et al., 2022) studied similar populations or research questions to previous studies, but did generate new findings or models of grief.

Two papers (Kachoyeanos & Selder, 1993; Wheeler, 2001) did not refer to any ethical considerations meaning it was unclear whether the studies were conducted ethically. The other papers all met this criterion by naming at least one ethical consideration, and five papers (Abdel Razeq & Al-Gamal, 2018; Entilli et al., 2021; Punaglom et al., 2022; Ross et al., 2018; Sterling et al., 2022) were deemed high quality in this area due to descriptions of several ethical considerations.

Finally, all studies demonstrated a degree of meaningful coherence in that they achieved the aims they set out to meet, and made some effort to link research findings to other literature or research. Studies that were rated as doing this to a high quality were those that clearly justified their aims and methodology, and integrated their findings with literature and research previously presented in the paper.

Overall, despite some areas of weakness, all papers were judged to be of sufficient quality for inclusion in the SLR synthesis.

2.4.3 Thematic Synthesis

A thematic synthesis of the final 19 papers led to the construction of three themes and nine subthemes, outlined in Table 5 and described in more detail below.

Table 5

SLR Thematic Synthesis: Themes and Subthemes

Theme	Subthemes
Changes in grief over time	Emotional changes Behavioural changes Cognitive changes
Grief and changing relationships	Relationships with deceased child Relationships with friends/ family Relationships with community/ society
No 'one way' to grieve	Grief as idiosyncratic Grief as non-linear Grief as never-ending

Theme 1: Changes in Grief Over Time. All papers reported that bereaved parents' grief changed over time. These changes have been broadly organised into three subtheme categories: emotional, behavioural and cognitive changes.

Subtheme: Emotional Changes. All papers reported that parents experienced intense emotions in the aftermath of their child's death. Several parents conveyed that these emotions were beyond anything they had experienced before, for example describing feeling "*the ultimate pain*"; "*like someone ripped my heart out*", (Tan & Ketola, 2013, p.145), or "*pure hell*" (Wheeler, 2001, p.56). Snaman et al. (2016) reported that parents described initial feelings that felt "too intense to survive" (p.1595)

and six papers reported that some parents experienced suicidal feelings (Alam et al., 2012; Kachoyeanos & Selder, 1993; Punaglom et al., 2022; Sterling et al., 2022; Tan & Ketola, 2013; Wheeler, 2001). Emotions named in the papers included shock, panic, anger, confusion, sorrow and guilt, as well as numbness and disconnection.

All papers stated that bereaved parents' emotional responses reduced in intensity and/ or frequency over time. However, all papers (regardless of inclusion criteria regarding years since bereavement) described participants experiencing ongoing emotional difficulty. Saiki-Craighill (2001) described parents experiencing continuing "waves of sadness" (p.266) over time, and a similar phenomenon was reported in five other papers (Calderwood & Alberton, 2023; Entilli et al, 2021; Fu et al., 2020; Malkinson & Bar-Tur, 2005; Sterling et al., 2022). All papers referred to ongoing longing and sadness, and several described persisting feelings of guilt, anger or depression (Abdel-Razeq & Al-Gamal, 2018; Alam et al., 2012; Calderwood & Alberton, 2023; Dutta et al., 2020; Entilli et al., 2021; Fu et al., 2020; Malkinson & Bar-Tur, 2005; Wheeler, 2001). There was a sense across all of the papers that whilst participants' emotions became more familiar and/ or controlled over time, they did not go away, and instead some parents described a process of accepting these emotions as a part of their lives, with one parent explaining "*my power to accept sadness has gotten stronger, this is not to say that I am less sad*" (Saiki-Craighill, 2001, p.265) and another describing his grief as "*a big stone... that I (will) ... carry... every day for the rest of my life... in the beginning the weight is incredible... but you learn to carry it... it becomes part of you*" (Sterling et al., 2022, p.5).

Several papers reported that over time, parents were gradually more able to experience positive emotions again (Abdel Razeq & Al-Gamal, 2018; Alam et al., 2012; Calderwood & Alberton, 2023; Entilli et al., 2021; Feigelman et al., 2020; Fu et

al., 2020; Ross et al., 2018; Wheeler, 2001). However, other parents gave the sense that their lives would always be 'tainted' by their loss for example *"joy is not there because he is missed all the time"* (Calderwood & Alberton, 2023, p.145). Other parents described how despite experiencing positive emotions they could quickly become upset and in deep grief again: *"Even though it has been ten years, sometimes I am laughing and suddenly I am crying"* (Tan & Ketola, 2013, p.147).

Subtheme: Behavioural Changes. Several studies reported that parents experienced periods of hypo- or hyperactivity after their child died (Abdel Razeq & Al-Gamal, 2018; Calderwood & Alberton, 2023; Dutta et al., 2020; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Malkinson & Bar-Tur, 2005). Hyperactivity was described as throwing oneself into work or distracting activity whereas hypoactivity included withdrawal and avoidance of the outside world, functioning *"on auto-pilot"*, *"going through the motions"*, or *"drifting through life"* (Wheeler, 2001, p.56).

Malkinson and Bar-Tur (2005) and Calderwood and Alberton (2023) described bereaved parents gradually returning to a normal routine over time, and Kachoyeanos and Selder (1993) described parents getting to a point of being ready to "enter the world again" (p.171). These papers all included parents who were further along in their bereavement journey (i.e. >10 years), and interestingly some papers who interviewed parents at an earlier time point (i.e. <2 years) found evidence of ongoing hyperactivity, for example *"it is better to do something, otherwise I would always think about my son... I feel better when I am busy"* (Chen et al., 2019, p.8); *"I'm always busy doing something and that's the way I operate"* (Entilli et al., 2021, p.4). This might suggest that a return to normal activity levels occurs later in the grief trajectory, although this difference may be influenced by other factors such as participants' cultural and social contexts.

Several papers reported that parents sought meaningful activity after their child had died such as fundraising, voluntary work, travelling or connecting with nature, which were considered helpful in facilitating their adjustment to living life again (Alam et al., 2012; Chen et al., 2019; Dutta et al., 2020; Entilli et al., 2021; Feigelman et al., 2020; Ross et al., 2018; Wheeler, 2001). Some papers reported that parents felt more able to engage in self-care and pleasurable activities over time, after initially avoiding these (Calderwood & Alberton, 2023; Chen et al., 2019; Entilli et al., 2021). In contrast, some parents described not finding activities pleasurable or meaningful anymore, and continuing to 'go through the motions': *"I try to focus on other things and it doesn't work. I just have to walk through the grief"* (Calderwood & Alberton, 2023, p.145); *"Nothing is significant except the great loss... I just keep going on. I have no other choice"* (Wheeler, 2001, p.58).

Subtheme: Cognitive Changes. All papers referred to cognitive changes that occurred in bereaved parents. Initial changes described included denial of the death and/ or feeling disconnected from reality (Calderwood & Alberton, 2023; Chen et al., 2019; Kachoyeanos & Selder, 1993; Saiki-Craighill, 2001; Wheeler, 2001). Some papers described parents going into a cognitive "fog" after their child died (Calderwood & Alberton, 2023; Kachoyeanos & Selder, 1993; Feigelman et al., 2020). Other papers reported that some parents initially sought answers and questioned why and how the death had occurred (Abdel Razeq & Al-Gamal, 2018; Calderwood & Alberton, 2023; Entilli et al., 2021; Punaglom et al., 2022; Sterling et al., 2022).

Several papers reported that parents experienced intrusive thoughts and images related to their child (Dyregrov & Dyregrov, 1999; Fu et al., 2020; Entilli et al., 2021; Malkinson & Bar-Tur, 2005; Tan & Ketola, 2013) or described parents' minds

being consumed by thoughts of their child (Calderwood & Alberton, 2023; Fu et al., 2020; Malkinson & Bar-Tur, 2005; Saiki-Craighill, 2001; Wheeler, 2001). Some papers reported that these experiences reduced over time (Calderwood & Alberton, 2023; Saiki-Craighill, 2001), but others described intrusive thoughts and images persisting over time (Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Fu et al., 2020; Tan & Ketola, 2013). Malkinson & Bar-Tur (2005) described parents being left with an “intensive inner life” (p.114) where their child remains central.

Several papers reported that in order to heal over time, parents had to go through a process of accepting that the death did happen (Calderwood & Alberton, 2023; Chen et al., 2019; Entilli et al., 2021; Ross et al., 2018; Sterling et al., 2022; Wheeler, 2001) as well as finding meaning and making sense of their child’s death (Abdel Razeq & Al-Gamal, 2018; Dutta et al., 2020; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Punaglom et al., 2022; Ross et al., 2018; Saiki-Craighill, 2001; Sterling et al., 2022; Wheeler, 2001). In addition, several papers described a need for parents to reframe or adjust their cognitions or narratives about the death (Abdel Razeq & Al-Gamal, 2018; Dutta et al., 2020; Entilli et al., 2021; Punaglom et al., 2022; Sterling et al., 2022). Some papers reported that over time, parents were able to think of things to feel grateful or positive about regarding their child’s life, which helped this process (Entilli et al., 2021; Feigelman et al., 2020; Saiki-Craighill, 2001; Sterling et al., 2022; Wheeler, 2001). Several papers (Dutta et al., 2021; Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Feigelman et al., 2020; Punaglom et al., 2022; Ross et al., 2018) described processes where parents felt they had learnt from their loss and were left with “*a larger perspective on life*” (Dyregrov & Dyregrov, 1999, p.655), or feeling that “*some things don’t matter at all anymore... priorities have changed*” (Calderwood & Alberton, 2023; p.13).

Overall, the papers reach some consensus in suggesting that the death of a parents' child causes significant emotional, behavioural and cognitive responses which are most distressing and disruptive in early grief. Whilst these responses may gradually reduce in impact over time, the papers suggest that they do not fully disappear and continue to cause difficulty. There was some variation between and within studies regarding these changes and whilst some of this may be explained by differences between studies (e.g. participant differences in culture, timepoint in grief and circumstances of child's death), there was also evidence of difference between participants within studies, perhaps suggesting that the grief trajectory is idiosyncratic, discussed further in theme 3.

Theme 2: Grief and Changing Relationships. This theme attempts to capture the bidirectional interactions between grief and relationships, with subthemes focusing on parents' relationships with their deceased children, friends, family, community and society.

Subtheme: Relationships with Deceased Child. All papers spoke about parents' relationships with their deceased children. Three papers described parents struggling to adjust to the loss of their parental role (Entilli et al., 2021; Tan & Ketola, 2013; Yamazaki, 2010). Other papers described a need in parents to reconstruct or continue a relationship with their child post-death (Calderwood & Alberton, 2023; Dutta et al., 2020; Malkinson & Bar-Tur, 2005; Saiki-Craighill, 2001; Yamazaki, 2010) or to keep their deceased children present in their lives (Alam et al., 2012; Calderwood & Alberton, 2023; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Punaglom et al., 2022). Yamazaki (2010) described parents reaching a final stage in grief of "always being together in a natural way" with their child (p.931) and Malkinson & Bar-Tur (2005) described a continued "central

presence of the deceased child within (parents') private world" (p.113), captured by parents in their study: "*he accompanies me every day, every hour, he is not erased*"; "*(my son) has more influence than a living person*" (p.114).

The papers described different ways that parents continued their relationships with their children post-death in order to keep them present. Some parents found holding onto physical mementoes and reminders of their child helpful (Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Tan & Ketola, 2013; Yamazaki, 2010) although Alam et al. (2012) found that the need to do this reduced over time for parents. Some parents found ways to memorialise their child including starting projects or fundraising in their child's name, erecting commemorative plaques, shrines or gravestones, creating video or written memorials, and regularly reminiscing with others about positive memories of the child (Alam et al., 2012; Dutta et al., 2020; Entilli et al., 2021; Feigelman et al., 2020; Kachoyeanos & Selder, 1993; Tan & Ketola, 2013; Wheeler, 2001). Other papers described ways that parents continued to communicate with their deceased children through writing and conversing with them, or feeling their spiritual presence (Entilli et al., 2021; Kachoyeanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Tan & Ketola, 2013; Yamazaki, 2010). All of these activities were described as helpful in facilitating the parents' grieving processes.

Subtheme: Relationships with Friends and Family. Several papers named family and friends as valuable sources of support for parents (Abdel Razeq & Al-Gamal, 2018; Calderwood & Alberton, 2023; Kachoyeanos & Selder, 1993; Punaglom et al., 2022; Snaman et al., 2016; Ross et al., 2018; Sterling et al., 2022; Wheeler, 2001; Yamazaki, 2010). Some parents described these relationships becoming closer (Alam et al., 2012; Calderwood & Alberton, 2023; Entilli et al., 2021;

Malkinson & Bar-Tur, 2005; Sterling et al., 2022; Wheeler, 2001), whereas others described friendships being lost (Alam et al., 2012; Calderwood & Alberton, 2023; Feigelman et al., 2020; Kachoyeanos & Selder, 1993) as well as tension in spousal relationships following bereavement (Alam et al., 2012; Calderwood & Alberton, 2023; Entilli et al., 2021; Fu et al., 2020; Malkinson & Bar-Tur, 2005; Sterling et al., 2022). Surviving children were described as a particular source of strength in coping with grief (Alam et al., 2012; Chen et al., 2019; Entilli et al., 2021; Malkinson & Bar-Tur, 2005; Tan & Ketola, 2013), although some parents felt they became over-protective of their surviving children as a result of grief (Alam et al., 2012; Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Malkinson & Bar-Tur, 2005; Yamazaki, 2010), for example: *“I watched (my surviving child) like a hawk, I was afraid for every step she took... I really lived in fear”* (Malkinson & Bar-Tur, 2005, p.117).

Several parents described others being initially supportive after their child's death but quickly becoming more distant over time (Alam et al., 2012; Calderwood & Alberton, 2023; Kachoyeanos & Selder, 1993; Tan & Ketola, 2013; Sterling et al., 2022). Some parents described feeling especially hurt when friends and family did not offer any support (Calderwood & Alberton, 2023; Feigelman et al., 2020; Kachoyeanos & Selder, 1993; Sterling et al., 2022) or made insensitive comments (Calderwood & Alberton, 2023; Feigelman et al., 2020; Kachoyeanos & Selder, 1993; Saiki-Craighill, 2001). Six papers highlighted that parents felt that their family and friends did not understand or appreciate the significance and longevity of their grief (Calderwood & Alberton, 2023; Dutta et al., 2020; Feigelman et al., 2020; Fu et al., 2020; Saiki-Craighill, 2001; Yamazaki, 2010), for example: *“they say, 'you look fine now'... I don't even have the energy to say that I'm not... it is hard to deal with*

the death, but friendships and family relationships bother me just as much" (Saiki-Craighill, 2001, p.263).

Some papers described bereaved parents' strong desire to keep talking about their deceased children (Alam et al., 2012; Dyregrov & Dyregrov, 1999; Feigelman et al., 2020; Kachoyeanos & Selder, 1993; Snaman et al., 2016; Tan & Ketola, 2013) and finding it difficult when friends and family did not mention their child or when this reduced over time, as the parent worried that the child would be forgotten (Alam et al., 2012; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Tan & Ketola, 2013), for example: *"he's definitely disappearing. I can see it now where he's disappearing from everything... I guess people don't talk about things like that, but I love talking about him"* (Entilli et al., 2021, p.4).

Several parents described feeling uncomfortable or pressured in social situations after bereavement and becoming more socially withdrawn or isolated as a result (Calderwood & Alberton, 2023; Entilli et al., 2021; Feigelman et al., 2020; Fu et al., 2020; Punaglom et al., 2022; Ross et al., 2018; Saiki-Craighill, 2001; Snaman et al., 2016; Yamazaki, 2010). Some papers reported that over time, parents were able to become more confident and socially active again (Calderwood & Alberton, 2023; Entilli et al., 2021; Saiki-Craighill, 2001) and found that relationships that had been negatively impacted by bereavement improved or stabilised (Alam et al., 2012; Calderwood & Alberton, 2023; Malkinson & Bar-Tur, 2005).

Subtheme: Relationships with Community and Society. Several papers described interactions between grief and parents' community and wider society. Three papers described parents finding their religious community to be a valuable source of support (Ross et al., 2018; Snaman et al., 2016; Tan & Ketola, 2013). Peer support communities were mentioned in 13 papers, with parents describing support

from other bereaved parents as uniquely valuable (Calderwood & Alberman, 2023; Chen et al., 2019; Dutta et al., 2020; Entilli et al., 2021; Feigelman et al., 2020; Fu et al., 2020; Kachoyanos & Selder, 1993; Ross et al., 2018; Saiki-Craighill, 2001; Snaman et al., 2016; Sterling et al., 2022; Wheeler, 2001; Yamazaki, 2010), as explained by one parent: *“only another bereaved parent knows exactly how you feel”* (Snaman et al., 2016, p.1599).

Two papers said that parents had found professional support such as counselling helpful (Dutta et al., 2020; Ross et al., 2018). Five papers reported that parents found professionals to be unhelpful or lacking in compassion regarding their grief, including those who had notified them of their child's prognosis or death, and healthcare professionals they had interacted with after the child's death (Dutta et al., 2020; Feigelman et al., 2020; Kachoyanos & Selder, 1993; Ross et al., 2018; Snaman et al., 2016). In addition, two papers described parents feeling abandoned by healthcare professionals after their child died, and feeling there was a lack of support available for them in their community (Abdel Razeq & Al-Gamal, 2018; Snaman et al., 2016).

Some papers described parents having to deal with societal expectations that parents should be able to “be strong and get on with life” (Kachoyanos & Selder, 1993, p.172) or not talk about the death too much (Dutta et al., 2020; Feigelman et al., 2020; Kachoyanos & Selder, 1993). Stigma was mentioned in four papers, in the context of the cause of death being drug overdose (Feigelman et al., 2020; Sterling et al., 2022) or occurring in cultures that believe in karma, where the death of a child might be associated with parental wrongdoing (Fu et al., 2020; Punaglom et al., 2022). All papers that mentioned stigma described parents finding it difficult to disclose or talk about their child's death with other people, and three emphasised the

increased importance of peer support, which was viewed as a safe space to discuss the child's death without judgement (Feigelman et al., 2020; Fu et al., 2020; Sterling et al., 2022).

Overall this theme suggests grief as shaped by relationships at multiple levels. Most papers highlighted that whilst others could provide important support to bereaved parents, they could also create additional pressure and distress for them, particularly when others did not seem to understand the parents' grief. An ongoing relationship with the deceased child was named in all papers as important for participants, which goes against models of bereavement that suggest attachments to the dead must be severed or that individuals should 'move on' in order to adjust to loss, and aligns with models that emphasise the importance of a continued relationship with the deceased (e.g. Klass et al., 1996).

Theme 3: No 'One Way' to Grieve. All papers referred to the fact that there is no set parental grief trajectory, as highlighted in the following subthemes which suggest that grief is idiosyncratic, non-linear and never-ending.

Subtheme: Grief as Idiosyncratic. All papers suggested that the grief trajectory was influenced by an individual's personal characteristics and/ or context. Several papers found that the grieving process varied between participants (Calderwood & Alberton, 2023; Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Feigelman et al., 2020; Malkinson & Bar-Tur, 2005; Ross et al., 2018; Snaman et al., 2016; Sterling et al., 2022; Wheeler, 2001).

Six papers discussed gender differences in the grief trajectory (Alam et al., 2012; Dutta et al., 2020; Dyregrov & Dyregrov, 1999; Entilli et al., 2021; Kachoyeanos & Selder, 1993; Yamazaki, 2010). All of these papers highlighted that

fathers tended to be more private and less willing to discuss their grief than mothers. Three papers (Entilli et al., 2021; Kachoyeanos & Selder, 1993; Yamazaki, 2010) referred to societal expectations about the male role, for example one mother said: *“Men are expected not to show emotions easily and also to support women. Besides, they need to go back to work immediately”* (Yamazaki, 2010, p.928). Alam et al. (2012) and Entilli et al. (2021) both found that fathers tended to distract themselves more initially by throwing themselves into work or other activities, although both papers reported that over time men were more able to express and discuss their grief, with a possible delayed grief response.

Seven papers discussed the role of spirituality and religion on the grief trajectory (Abdel Razeq & Al-Gamal, 2018; Alam et al., 2012; Entilli et al., 2021; Punaglom et al., 2022; Saiki-Craighill, 2001; Tan & Ketola, 2013; Wheeler, 2001). All of these papers described spiritual and religious beliefs as being protective and helpful in the grief process, for example: *“God gave me a gift and he took her back, that is the idea that kept me strong”* (Abdel Razeq & Al-Gamal, 2018, p.141). Four papers reported that some parents found their religious or spiritual beliefs to be greater following bereavement (Entilli et al., 2021; Punaglom et al., 2022; Tan & Ketola, 2013; Wheeler, 2001), however two papers reported that some parents became disillusioned with their beliefs following the death of their child (Alam et al., 2012; Wheeler, 2001).

Cultural context was discussed in six studies, all of which were conducted in East or South-East Asia (Chen et al., 2019; Dutta et al., 2020; Fu et al., 2020; Punaglom et al., 2022; Saiki-Craighill et al., 2001; Yamazaki, 2010). Two of these papers described cultural rituals that were helpful in the grieving process (Punaglom et al., 2022; Saiki Craighill et al., 2001). Four papers spoke about cultural influences

that exacerbated grief, including parents believing the death was an act of karma (Fu et al., 2020) or that they had dishonoured their ancestors (Chen et al., 2019), parents feeling unable to talk about the death due to cultural taboo (Dutta et al., 2020), and cultural norms or expectations related to having fewer children making child bereavement harder to cope with (Fu et al., 2020; Yamazaki, 2010).

Subtheme: Grief as Non-Linear. Thirteen papers described the grief process as being non-linear, fluid, or changeable (Calderwood & Alberman, 2023; Chen et al., 2019; Dutta et al., 2020; Entilli et al., 2021; Fu et al., 2020; Kachoyanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Ross et al., 2018; Saiki-Craighill, 2001; Snaman et al., 2016; Sterling et al., 2022; Tan & Ketola, 2013; Yamazaki, 2010). Some papers that had attempted to produce a model of the grief trajectory highlighted that processes were not unidirectional and that some parents may repeat or skip parts of the grief process (Calderwood & Alberman, 2023; Dutta et al., 2020; Yamazaki, 2010).

Several papers described that despite time elapsing, parents continued to have peaks of grief, often triggered at specific anniversaries or milestones (Entilli et al., 2021; Kachoyanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Sterling et al., 2022; Tan & Ketola, 2013) or by stimuli reminding the parents of the child or their death (Calderwood & Alberman, 2023; Fu et al., 2020; Kachoyanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Saiki-Craighill, 2001; Sterling et al., 2022; Tan & Ketola, 2013). Parents further along in their bereavement (>15 years) stated "*it feels like it just happened*" (Dyregrov & Dyregrov, 1999, p.653) and "*his death hurts today exactly as it hurt then*" (Malkinson & Bar-Tur, 2005, p.115), suggesting grief that did not get easier over time. Malkinson & Bar-Tur (2005) described parental grief as becoming more burdensome in older age, due to increased loneliness and time to ruminate.

Subtheme: Grief as Never-Ending. Eleven papers highlighted that the grief process was infinite (Abdel Razeq & Al-Gamal, 2018; Calderwood & Alberton, 2023; Chen et al., 2019; Dutta et al., 2020; Kachoyeanos & Selder, 1993; Malkinson & Bar-Tur, 2005; Snaman et al., 2016; Sterling et al., 2022; Tan & Ketola, 2013; Wheeler, 2001; Yamazaki, 2010). These papers were often those that interviewed parents further along in their bereavement years, and parents described their grief as “*terminal*” (Tan & Ketola, 2013, p.147) or “*never-ending*” (Snaman et al., 2016, p.1596). Sometimes the loss was described as physical, for example one parent stated “*a part of me is cut off*” (Wheeler, 2001, p.58), and Abdel Razeq and Al-Gamal (2018) described parents being left with a permanent “scar” (p.142). Tan & Ketola (2013) reported that parents “said the thought of resolving their bereavement was repulsive” (p.147). Several papers highlighted that the never-ending nature of grief often did not match other people or society’s expectations of the grief trajectory (Alam et al., 2012; Entilli et al., 2021; Feigelman et al., 2020; Fu et al., 2020; Kachoyeanos & Selder, 1993; Sterling et al., 2022; Yamazaki, 2010). One parent 12 years into their bereavement highlighted that “*some people say I am stuck in my grief but I don’t really think I’m stuck in it. I just think you never really do get over the death of your child*” (Calderwood & Alberton, 2023, p.13).

Overall this theme suggests grief that is unique for each individual and is neither finite nor linear, all of which goes against a staged or sequential understanding of grief. This theme may align with non-linear understandings of grief such as the dual process model (Stroebe & Schut, 1999), which suggests that bereaved individuals continue to oscillate between being immersed in their loss and being able to engage in life outside of loss, as well as the continuing bonds theory (Klass et al., 1996) which proposes a never-ending attachment to the deceased, and

Tonkin's (1996) suggestion that whilst an individual can 'grow' their life outside of grief, their grief does not shrink or go away over time.

2.5 Summary and Critical Appraisal of SLR

This SLR set out to answer the question "*what is known about how bereaved parents experience grief over time?*". In summary, the 19 papers appeared to reach consensus in several ways. Firstly, all papers described parents experiencing intense emotions at the beginning of their grief trajectory, which eased over time but never fully disappeared. In addition to emotional changes, cognitive changes were highlighted by all papers as being important in the process of adjusting over time to bereavement. All papers commented on the important influence that relationships with others can have on the grief trajectory, including the relationship with the deceased child, with an appeared need for parents to continue and reconstruct this relationship over time. Finally, despite these common features of grief trajectories, all papers highlighted in some way that the grief process is idiosyncratic and dependent on an individual's characteristics and context. This might suggest that grief is influenced by a complex intersection of cultural, social and individual factors, which is in line with previous research regarding protective and risk factors for bereaved parents (e.g. Wijngaards-de Meij et al., 2005; Zhao et al., 2022), and might explain the differences between participants within and across studies, as highlighted throughout the synthesis.

The thematic synthesis demonstrated a number of similarities between study findings, with a number of subthemes being present across all 19 papers, irrespective of nature, context or time of death. Studies that included no inclusion or exclusion criteria regarding the ages or causes of death of participants' children also reported high levels of similarity in participants' experiences (Calderwood & Alberton,

2023; Tan & Ketola, 2013; Wheeler, 2001), perhaps suggesting that the experience of parental grief is not largely affected by the child's age or circumstances of death. Similarly, the SLR included papers from a range of geographical locations, but thematic synthesis demonstrated some common threads between these studies. Cultural context was named as influencing the grief trajectory in six papers (Chen et al., 2019; Dutta et al., 2020; Fu et al., 2020; Punaglom et al., 2022; Saiki-Craighill et al., 2001; Yamazaki, 2010), all of which were conducted in East or South East Asia. Two papers were situated in the Middle East (Abdel Razeq & Al-Gamal, 2018; Malkinson & Bar-Tur, 2005), and the other 10 papers were all conducted in Westernised countries with mainly white participants. This speaks to a need to conduct research regarding the experiences of parental grief over time in other geographical and cultural contexts.

2.6 SLR Strengths, Limitations and Implications

This SLR has implications for both clinical practice and future research. The theme identified across papers of there being no 'one way' to grieve challenges linear and sequential conceptualisations of grief. This has important clinical implications as professionals supporting bereaved parents will need to understand that parental grief is never-ending and does not develop in a linear fashion. Bereaved parents have highlighted across papers the value of good relationships, peer support, meaningful activity and finding ways to keep their child present, which may inform the support offered to them. Finally, the notion of grief being idiosyncratic is important and professionals should make efforts to understand parents' unique experiences of grief, and to consider these within cultural and social contexts.

Overall, this SLR has strengths in terms of inclusion of papers from a variety of countries, with participants from different contexts (i.e. different ages, time since

and cause of child death). The SLR reached some consensus between papers which has implications, as discussed. Despite this, it should be noted that the SLR was limited in terms of only including literature that was published in peer-reviewed journals, in English language. This may have caused bias in the papers included, particularly as it is known that research conducted by and with white, Western people is overrepresented in peer-reviewed journals (Bancroft et al., 2022).

2.7 Current Study Rationale and Aims

2.7.1 Rationale for Current Study

None of the studies identified in the SLR were conducted in the UK, suggesting that research into bereaved parents' experiences of grief over time in this country are scarce. Although other Western countries were represented in the SLR, the UK is arguably a unique context with regards to grief, with literature suggesting that the UK tends to view grief as a particularly private experience, possibly influenced by social narratives related to the British having a 'stiff upper lip' – i.e. being restrained or reserved with their emotions (Dixon, 2015; Noakes, 2015; Walter, 1997). The current study will therefore address a gap in the literature by investigating bereaved parents' experiences of grief over time in a UK context, which may have particular idiosyncrasies unique from other cultures.

This study will take the form of a narrative inquiry. Narrative inquiries involve gathering, analysing and representing people's stories (Wang & Geale, 2015), which is a particularly useful method for tracking evolving narratives of experiences over time. None of the papers included in the SLR used narrative methodologies, and it is felt that this design will add to the evidence base in the following ways:

1. *Stories as individual* – one of the SLR findings was that all papers highlighted the idiosyncratic nature of grief. A benefit of narrative analysis is that it is one of the few qualitative methodologies that allows for individual stories to be represented intact (Josselson & Hammack, 2021). This is in contrast to the papers included in the SLR which all amalgamated participants' experiences into themes or models of grief. It is therefore hoped that exploring individual narratives through conducting a narrative inquiry will enrich the understanding of the individual nature of parental grief.
2. *Stories as co-constructed* – as highlighted in the SLR, previous research into parental grief over time has not drawn attention to the impact of the researcher's positioning and context. Narrative analysis argues that stories are co-constructed between teller and receiver within a particular context and time (Squire et al., 2014), therefore this approach will allow for researcher self-reflexivity and consideration of context which may have been lacking in previous research.
3. *Stories as healing?* – The SLR highlighted a number of cognitive and sense-making processes thought to be important in adjusting to bereavement. It has been suggested that narratives hold importance in coping with stressful events (East et al., 2010; Neimeyer & Levitt, 2001) and individuals may feel particularly driven to storytelling to help make sense of loss and bereavement (Bosticco & Thompson, 2005; Gilbert, 2002). It is therefore hoped that exploring how and why parents tell the stories of their loss may further inform the evidence base about what helps parents to adjust and cope with their bereavement.

2.7.2 Aims and Research Questions

This study aims to explore the stories bereaved parents tell about their experiences of grief over time, in particular, stories they tell about adjusting to living life following bereavement. The research questions this study hopes to answer are:

1. How do bereaved parents story their experiences of grief over time?
2. What do these stories suggest about how parents have adjusted to the death of their child?

Chapter Three: Methodology

3.1 Chapter Overview

This chapter focuses on the study methodology, outlining the research design and study procedures including recruitment, data collection and analysis. Ethics, reflexivity and quality are also considered and discussed.

3.2 Design

This study aims to explore the stories bereaved parents tell about their experiences of grief over time, particularly the stories they tell about adjusting to living life following bereavement. In order to address these aims, a qualitative design will be used in the form of a narrative inquiry, which considers stories as data. Stories will be gathered from bereaved parents via semi-structured interviews, and analysed using narrative analysis methodology.

3.2.1 A Case for Narrative Inquiry

Humans are constantly expressing themselves through storytelling, and it is thought that this is an important process for making sense of self, events and the world (Worth, 2008). Narrative inquiry concerns itself with the collection and interpretation of stories, which are considered to be subjective reconstructions of experiences (Moen, 2006). It has been suggested that storytelling can be particularly important for grieving individuals (Bosticco & Thompson, 2005; Gilbert, 2002), and this connects with Neimeyer's (2001a) "meaning reconstruction" model of grief which emphasises the importance of sense-making in adjusting to bereavement. Research into bereaved parents' experiences of research participation has found that parents express gratitude for the chance to tell their "story", and have particularly described interviews as providing an opportunity to talk about their child, as well as facilitating

further sense-making regarding their loss (Butler et al., 2018; Dyregrov, 2004). A narrative inquiry could therefore offer insight into how bereaved parents make sense and therefore adjust to their losses, and the collection of stories via oral interviews may offer some benefits to participants.

Bereaved parents who have taken part in research have described particularly valuing the chance to tell their 'complete' story, as a way of remembering and honouring their child's life (Butler et al. 2018; Dyregrov, 2004). This might be particularly important given research findings that bereaved parents can feel 'silenced' by society (Kachoyeanos & Selder, 1993; Maple et al., 2009). In light of this, one important benefit of narrative analysis is that it will allow for parents' stories of their children to be preserved and presented intact (Josselson & Hammack, 2021). This is in contrast with other qualitative approaches (such as IPA, grounded theory or thematic analysis), which seek to amalgamate participants' experiences into themes or models. A narrative inquiry is therefore felt to be the most appropriate and ethical choice of methodology for achieving the aims of this research.

Narrative research can utilise a number of different methodologies and approaches, which overlap and are often used in conjunction with each other (Squire et al., 2014). Approaches include thematic narrative analysis, which concerns itself with story content (Riessman, 2008) and structural narrative analysis, which focuses on the way stories are organised and composed (Labov, 1972). Thirdly, performance analysis focuses on how and why stories are 'performed', including how stories are shaped by their context and audiences (Riessman, 2008). These three approaches are often used in combination in what can be termed an "integrative approach" to narrative analysis (Bamberg, 2020).

Another approach which further considers story context is constructionist narrative analysis methodology. This approach considers stories as socially constructed within interpersonal, social, cultural and political contexts (Esin et al., 2013). In this sense, narratives are viewed as relational, or “forms of social action” (Sparkes & Smith, 2008, p.299), between the teller and multiple audiences, including those listening to the story as well as wider sociocultural ‘audiences’. This is a socially-oriented approach to narrative analysis, which differs from individually-oriented narrative approaches that consider narratives as windows into individuals’ internal experiences or realities (Esin et al., 2013; Squire et al., 2014).

For the purposes of this study, an integrative approach to narrative analysis including thematic, structural, and performance analysis will be used, in order to allow for the analysis of different ‘layers’ of participants’ stories. Furthermore, analysis will be informed by a constructionist approach to narrative inquiry, which considers stories as co-constructed, in line with this study’s epistemological position (outlined in Chapter 1).

3.2.2 Expert by Experience (EbE) Consultation

This research was conducted alongside a charity based in a large English city that offer support to bereaved parents who have lost a child under any circumstances. This support mainly takes the form of peer support groups, and group facilitators and charity staff are all bereaved parents themselves. The charity supported the study by facilitating recruitment and by providing EbE consultation. One member of staff at the charity acted as a key EbE who was consulted at various stages of the study design, and two other members of staff offered EbE input regarding the study materials and interview schedule. Examples of how EbE consultation impacted the study will be given at relevant sections of this chapter.

3.3 Procedure

3.3.1 Sampling Strategy

A self-selecting sampling method was used, with the aim of recruiting 5-8 participants. Wells (2011) recommends a sample size of at least 5 participants for narrative inquiry, although also highlights that narrative methods do not lend themselves to large sample sizes due to the need for rich in-depth accounts to be collected and analysed. This range was therefore felt to be appropriate for the scope of the current research. The study inclusion criteria and the rationale for each of these is provided in Table 6.

Table 6

Participant Inclusion Criteria

Inclusion Criteria	Rationale
1. Has experienced the death of their child	In line with research question
2. Self-identifies as having gradually adjusted to living life without their child	In line with research question
3. Has had some contact with the parent bereavement charity (either as a member or support group facilitator)	Necessary due to remits of advertisement and recruitment methods; also, ethical as ensured participants were linked up to support if required
4. Is fluent in English language	Necessary due to the limitations of my own language and research abilities ⁹

There were no inclusion criteria related to the cause of death or age of child.

This was aligned with the charity's ethos, as highlighted in EbE consultation, which

⁹ This was particularly the case given the centrality of language and meaning-making in narrative research (Riessman, 2008), which would make data gathering via interpreters more challenging.

views all types of parental grief as equal. In addition, this decision was informed by the SLR, which found a number of similarities across papers irrespective of circumstances of death or age of child.

A decision was made to have no inclusion criteria regarding the length of time that had passed since deaths, as no consensus has been reached in previous research regarding timescales of parental grief, and the SLR highlighted the grief trajectory as never-ending and idiosyncratic. There was, however, a need to identify parents who had made some adjustment to their loss, in order to address the research questions. This led to the development of the second inclusion criterion which was left open to the interpretation of parents themselves, using the term “gradually adjusted to life”, as suggested by EbEs. A decision was made to include group facilitators within the recruitment pool as they were likely to meet other inclusion criteria¹⁰.

3.3.2 Recruitment

The study recruitment strategy was to recruit via the parent bereavement charity's online platforms and mailing list (which consists of bereaved parents who have accessed support from the charity and/ or been facilitators of peer support groups), and via snowballing (word-of-mouth) methods.

The charity advertised the study on their social media, blog and website (Appendix C) as well as distributing a study advertisement leaflet (Appendix D) via email to the charity mailing list. Advertisement was facilitated by the charity staff member who acted as the study's key EbE. Parents that were interested in taking part in the study were advised to contact either myself or this staff member (who

¹⁰ This did not include staff who were already acting as EbEs.

then forwarded parents' details to me) via email. Eight parents expressed interest in participating and were emailed a study information sheet (Appendix E) with more details about the research, which they were asked to review, before contacting me if they still wanted to take part. Six parents confirmed they would like to participate, and I contacted each of them via phone or email to gather some brief information, (i.e. confirming that inclusion criteria were met) and to arrange interviews at a convenient time and location for them.

The final two participants recruited both heard about the study via word-of-mouth from other participants who had completed the interview, and contacted me to ask if they could participate. Both participants met all inclusion criteria and were sent the study information sheet before interviews were arranged. After completion of the eighth interview, it was felt that data was sufficiently rich for narrative analysis to be conducted, and that there was reasonable coherence between participants' accounts, therefore no further rounds of recruitment were conducted.

3.3.3 Participants

Eight participants were recruited and interviewed. Demographic information for participants is displayed in Table 7.

Table 7*Participant Demographic Information*¹¹¹²

Pseudonym	Age	Gender	Ethnicity	Age and gender of child who died	Years since child died
Alison	60	Female	White British	Early 20s, male	10
Jane	75	Female	White British	Mid 20s, female	20
David	60	Male	White British	Early 20s, female	5
Charlotte	45	Female	White British	1-6 months, male	10
Fiona	55	Female	White British	2-5 years, male	10
Kath	60	Female	White British	5-10 years, female	15
Sally	60	Female	White Irish	2-5 years, female	20
Teresa	70	Female	White British	Mid 20s, female	15

3.3.4 Development of Interview Schedule

Narrative research literature suggests that interviewers can suppress narratives if they interrupt or guide the interview content too heavily (Esin, 2011), and Elliott (2005) suggests that most participants will tell their stories with little prompting and that the interviewer's role should be to provide space for this. With this in mind, the interview schedule was kept to three key questions, which were open and aimed to invite participants to tell stories related to the research questions. Questions were followed by a series of additional prompts to use as required, and a statement was included at the beginning of the schedule to say that I would ask some questions but would mainly be listening to the participant's story.

¹¹ Participants are presented in order from earliest to latest date of interview.

¹² In order to preserve anonymity, pseudonyms are used and some details are reported as approximations (participant ages and years since the child died), or as ranges (age of child who died).

The interview schedule was reviewed by my supervisory team who made some suggestions regarding additional prompts and wording of questions to elicit stories related to the research questions. The schedule was also reviewed by EbEs and changes were made to some of the language used in order to reflect the language used by bereaved parents themselves, for example replacing the word “loss” with the word “death”, felt to be more direct.

Once the interview schedule had been amended according to these suggestions, I completed a pilot interview with the research key EbE, via Zoom. The EbE gave positive feedback regarding this experience and the schedule was therefore not amended any further. A copy of the final interview schedule is provided in Appendix F.

3.3.5 Interview Process

Participants were given the choice for interviews to be conducted remotely or face-to-face. This decision was made in order to be considerate of participant needs in light of the sensitive interview topic, and was informed by previous research that has found that video and face-to-face interviews yield similar results (Krouwel et al., 2019). Face-to-face interviews were conducted at participants' homes, and remote interviews were conducted via Zoom. All participants who chose to complete the interview remotely did so from their own homes. At the beginning of the interview, participants were asked to confirm that the interview location would offer a private and uninterrupted space for at least 90 minutes. Table 8 shows the interview format and length for each participant.

Table 8*Interview Formats and Lengths*

Participant	Interview format	Interview length
Alison	Remote	1hr 47 minutes
Jane	Face-to-face	1hr 15 minutes
David	Face-to-face	1hr 21 minutes
Charlotte	Remote	1hr 18 minutes
Fiona	Remote	1hr 23 minutes
Kath	Face-to-face	1hr 55 minutes
Sally	Remote	1hr 16 minutes
Teresa	Face-to-face	1hr 38 minutes

Prior to the start of interviews, consent was reviewed and confirmed and participants were asked to provide their demographic information; recording equipment was then set up, and the interviews were conducted. Following interview completion, the recording was stopped and a debrief was provided, which included checking in with how the participant was feeling, inviting any reflections regarding the interview experience, and confirming the next steps regarding analysis and dissemination of the research. Participants were invited to contact me should they have any concerns or questions related to the research, including if they wished for any information to be omitted from their transcripts. Only one participant contacted me to ask for a small part of their transcript to be amended to further preserve their anonymity, which was agreed to.

3.4 Ethical Considerations

3.4.1 Ethical Approval

Ethical approval of the study was obtained from the University of Hertfordshire (see Appendix G).

3.4.2 Informed Consent

All individuals who expressed interest in taking part in the study were sent a study information sheet (Appendix D) which detailed the study procedures and included information about the voluntary nature of participation as well as consent and right to withdraw.

All participants completed and signed a written consent form (Appendix H) prior to being interviewed, which included consent for the interviews to be recorded. Prior to interviews, consent was confirmed and participants were given the opportunity to ask questions.

3.4.3 Considerations Regarding Online Data Collection

As some of the interviews were conducted remotely, ethical guidance regarding online data collection was consulted (Franzke et al., 2019). In line with recommendations by Yusof et al. (2022) this study allowed for consent forms to be signed electronically, and forms were reviewed with participants prior to interviews. As per guidance by Lobe et al. (2020), Zoom meetings were set up requiring passwords to enter and with a 'waiting room' feature enabled, to prevent other people from entering the meeting.

3.4.4 Confidentiality, Anonymity and Data Management

Interviews were recorded via Zoom (audio recording only for face-to-face interviews, and video and audio recording for remote interviews). Zoom meetings were set up through a University of Hertfordshire account, which allowed recordings to automatically be saved to a secure, password-protected drive. Participants were made aware that recordings of their interviews would be deleted once the write up of the study was complete.

All interviews were transcribed and anonymised - participants and their families were assigned pseudonyms and all identifying information such as locations was omitted or altered. Whilst anonymity was preserved for the purposes of this thesis, participants were given the choice of remaining anonymous or using their real names should results be disseminated to the charity or published in a journal¹³; participants had different preferences regarding this, which were noted. Transcripts, participant consent forms and demographic details were stored on a secure drive in separate password-protected folders. Participants were asked to give (optional) permission for their anonymised transcripts to be stored for up to ten years by the University of Hertfordshire for possible further analysis, which they all consented to.

3.4.5 Participant Wellbeing

As mentioned earlier in this chapter, bereaved parents who have previously participated in research have described positive experiences regarding participation, particularly valuing the chance to talk about and remember their child (Butler et al. 2018; Dyregrov, 2004). This opportunity might not be provided by others in bereaved

¹³ This option was given as it has been discussed in bereavement literature that participants often wish to use real names for themselves and the deceased, to take ownership of their words given the often-silencing nature of bereavement, and to memorialise their deceased loved ones (Scarth, 2016).

parents' lives (Dutta et al., 2020; Feigelman et al., 2020), particularly as other people can perceive bereaved parents as vulnerable, or likely to get upset if their child is mentioned (Hastings, 2000; Butler et al., 2018). It is therefore felt that the inclusion of bereaved parents in qualitative research is important, and can be a positive experience for them, so long as appropriate ethical considerations are made (Dyregrov, 2004).

Discussions regarding managing risk of participant distress were had with my supervisory team. The study inclusion criteria were developed with risk in mind, recruiting participants that a) identified as having gradually adjusted to the loss of their child (i.e. unlikely to be experiencing acute grief), and b) were known to a parental bereavement charity (indicating that participants had accessed support and/or could do so if required after the interview). Participants were also given a choice of being interviewed remotely or face-to-face to try and make the interview as comfortable as possible for them.

The possible emotional impact of the interview was highlighted in the study information sheet, which was sent to all participants. This information sheet highlighted that I, the interviewer, am a trainee clinical psychologist with experience of supporting people in distress. The information sheet also made clear the remits of confidentiality (i.e. that if I were to have any concerns about participant safety, I would have to break confidentiality in order to share risk information as required). Prior to all interviews starting, this information was reviewed, and participants were reminded that they could pause or stop the interview at any stage, as well as choose to not answer any questions.

Throughout the interviews, I remained mindful of participants' distress levels, and participants interviewed remotely were asked to keep their cameras on for the

duration of interviews to facilitate this. Furthermore, for remote interviews, as per ethical guidelines and advice related to online research (British Psychological Society, 2021; Irani, 2019), I ensured that I was in a private, well-lit space with a neutral background, that I positioned my camera at eye level, that the participant's video display filled my whole screen and that I made 'eye contact' with the camera on my device, all for the purposes of rapport and participant comfort.

In line with guidance by Whitney and Evered (2022), I planned to initially ask participants if they would like to pause the interview if they showed signs of increasing distress, however no significant concerns regarding participant wellbeing arose in the study, and all participants were able to complete the interview without pausing or stopping. After each interview I checked how participants had found the interview and how they were left feeling. I also provided participants with a debrief sheet (Appendix I) including the details of people and organisations to contact if they needed further support, sent via email to those interviewed remotely.

3.5 Analysis

3.5.1 Transcription

The analysis of data begins at transcription and "how content is both heard and perceived by the transcriptionist and the form and accuracy of its transcription play a key role in determining what data are analysed and with what degree of dependability" (Stuckey, 2014, p.6). This is particularly relevant given narrative analysis' attention to subtle nuances in language and performance (Riessman, 2008). With this in mind, I decided to transcribe all eight interviews myself.

Poland's (2001) abbreviated guide to transcription methods (Appendix J), was used to guide my transcription. This approach enhances verbatim transcripts by

allowing for the representation of occurrences such as pauses, emphasised words or sounds, interruptions and overlapping speech.

3.5.2 *Analysing Stories*

There is no formal way of completing narrative analysis, and several possible analysis methodologies exist (Wells, 2011). As discussed, this study sought to use an 'integrative' approach to narrative analysis (Bamberg, 2020), combining thematic, structural and performance narrative approaches. To guide analysis, a framework (Table 9) was developed and used, based on narrative literature (Bengtsson & Andersen, 2020; Esin, 2011; Riessman, 2008; Wells, 2011).

Table 9

Framework Used to Guide Analysis

Analysis Approach	Focus	Questions to Consider
Thematic	Content (what is said)	<ul style="list-style-type: none"> • What stories are being told? • What themes or patterns emerge in the story?
Structural	Structure (how the story is put together)	<ul style="list-style-type: none"> • How is the story ordered and organised? • How does the story begin, develop and end? • How is the story told? Does it flow or seem fragmented?
Performance	Context (who the story is directed to, when and why it is told)	<ul style="list-style-type: none"> • How might context (when and where the story was told, who it was told to) be influencing the story? • How are the narrator, audience and others positioned in the story? • How is the story co-constructed? • How are language and emotion used in the storytelling, and what might this indicate? • What is left unsaid in the story? • What societal and cultural discourses might the story be drawing upon?

All eight interviews were transcribed by myself which allowed for a process of immersion in the data. Following this, the interview transcripts were read and re-read whilst listening to audio recordings of the interviews. The aforementioned framework was used to code transcripts line-by-line according to content, structure, and performance. Microsoft Word was used to highlight and annotate transcripts for coding and an extract of an analysed transcript is provided in Appendix K.

Following coding, transcripts were reviewed separately, and notes were made regarding my impression of each individual's story. After this, accounts were considered collectively, reviewing similarities and differences, and narratives that existed across accounts. This process also included consideration of how collective narratives connected or diverged with existing literature.

3.5.3 Representation of Stories

Careful consideration should be given to how stories are presented within narrative inquiry (Kim, 2016). I have chosen to present a short summary of each individual's story, including my impressions regarding the themes, structure and performance of each account. Following this, I present the collective narratives constructed across accounts. It is important to consider that in line with a social constructionist epistemology, my 're-telling' of participants' stories will in itself be the construction of a narrative, inevitably influenced by my own context (Esin et al., 2013). In order to address this, direct quotes from participants are included throughout and I have engaged in processes of reflexivity.

3.5.4 Reflexivity

"All qualitative research is contextual" (Dodgson, 2019, p.220) and a researcher's personal context will inevitably impact both the research process and

interpretation of findings. Reflexivity in research is the process of a researcher acknowledging and reflecting upon their subjective influence on the research, and is considered an essential element of good quality qualitative research (Jootun et al., 2009). This is particularly relevant in narrative research which concerns itself with how stories are co-constructed between teller and 'other' (Squire et al., 2014).

In line with recommendations by Etherington (2006), I used a reflexive journal (extract in Appendix L) to record my thoughts, feelings and reflections throughout the research process, which were discussed with my supervisory team. This included reflections regarding the potential influence of my outsider researcher status (Joseph et al., 2021). When reporting the findings of this study I have attempted to use a reflexive voice by writing in the first person and including myself in some of the interpretations.

3.6 Ensuring Quality

The quality criteria by Tracy (2010) were considered throughout the research process, described in more detail in Chapter 2, and used to review the study's quality in Chapter 5.

Due to the social constructionist epistemological stance of this research, it was not felt appropriate to member-check findings with participants as this would have led to further 'co-construction' of narratives; it was therefore necessary to use other methods of quality checking. Extracts of anonymised transcripts and findings were shared and discussed with my supervisory team and a peer working group, in order to check the resonance of my interpretations and to reflect upon my own construction and meaning-making of the data.

Chapter Four: Findings and Discussion

4.1 Chapter Overview

In this chapter, I present the results of the narrative analysis. I first outline an overall impression of each participant's account, before considering the accounts collectively, including how they connect and diverge from each other and the wider literature. Quotes from participants are included throughout, emphasised by the use of italics.

4.2 Individual Stories

4.2.1 Alison's Story

Alison is 60-years-old and has two children with her husband. Ten years ago, Alison's eldest child Ben died following an accident, when he was in his early 20s.

Alison told a tragic story of a *"lovely"* young person who, despite Alison having had *"quite a difficult time with him as a teenager"*, was *"just in a really good place"* at the time of his death. Alison's story communicated the injustice of spending *"so long"* working through the *"difficult time"* only for Ben to die.

A theme of injustice continued, with Alison communicating that *"you only get one life, why did we have to get this life, why did this have to happen?"*. These questions seem to have led Alison to consider whether Ben's death was a *"punishment"*, with thoughts that *"if I was a better person, it wouldn't have happened"*. Alison specifically spoke about wondering if she could have been *"a better mother"*, possibly influenced by pervasive societal discourses around mother-blaming (Richardson et al., 2014; Sommerfield, 1989), highlighted when Alison said *"as a mother, I think that's your role... to look after your kids"*.

A story of injustice led on to a story of Alison feeling *“bitter... with people... I just feel angry that they’ve got a family still”*, for example *“when I see a mother and son, I just can’t cope with that... I should have been able to go out with Ben”*. Alison went on to say that she can *“deal with (other people) better now”* and told a story of *“gradually”* starting to *“feel better”* over time, largely aided by the *“tremendous support”* she receives from others. Alison shared that on a recent trip *“for the first time... I felt happy, and I didn’t feel guilty for feeling happy”*. Overall, Alison told a story of making progress, but said she still does not *“like the world very much”*, ending her story by saying: *“you get to a place where you can manage your life. But, I’ll always resent the fact that this is my life”*.

Alison’s story flowed with little prompting, and felt honestly told and raw, which contrasted with Alison saying she often feels the need to *“put on an act”* around others. It is possible that the interview context facilitated this, and it may be that Alison wanted to communicate the gravity of her grief to a wider audience. There were times in the interview when I felt pulled into a position of wanting to increase hope; for example, when Alison spoke about *“the hardest thing”* being never seeing Ben again, I changed the subject to the more hopeful topic of her surviving daughter. My urge to draw Alison’s attention to positives may mirror societal discomfort and pity towards bereaved parents (Heo et al., 2022; Riches & Dawson, 1996), with Alison noting that others can be *“nervous”* around her or *“don’t know what to say”* and that she dislikes *“people feeling sorry for me”*. Alison responded to my change of the subject by continuing with a story of difficulty, and said *“I do tend to always look at the negative”*, perhaps communicating to me that there is no way to put a positive ‘spin’ on events, echoed in her statement: *“no-one can make you feel better, that’s the thing”*.

4.2.2 Jane's Story

Jane is 75-years-old and is married to Ken. Twenty years ago, their only child Elizabeth died following an accident, when she was in her mid-20s.

Jane told a rich story of Elizabeth's life which focused on her positive qualities: *"she lived life to the full... in every respect"*; *"she was so full of life"*. Jane told these stories with a great deal of conviction: *"she went to university that she loved 200%"*; *"she was everybody's friend"*, and a narrative of Elizabeth living a full life that impacted others seemed important for Jane to communicate. There were times when Elizabeth herself was brought into the interview, often with lightness reflective of Jane's descriptions of Elizabeth's personality, for example: *"she laughs at me saying this now, I can hear her"*. This implied a continued relationship, added to when Jane said: *"the fact that I talk to her... helps me, and I will continue"*.

In contrast to the rich stories told about Elizabeth, Jane often spared detail or spoke with more ambiguity when talking about her own grief, for example saying that initially she *"couldn't cope very well"* but not divulging any further detail, possibly suggesting that the early grief response was difficult for Jane to think or talk about. Jane's story of her grief over time often featured plots related to perseverance, for example *"Ken's cousin said... 'you can either be the tragic hero or get on with life' and that's the truth of it... nobody likes somebody who's drowning in sorrow all the time, so you don't have a choice"*. This attitude of perseverance is likely influenced by social discourses, and was reflected in Jane's storytelling in that she sometimes seemed to avoid dwelling on negative experiences and reverted to telling more positive stories. For example, Jane often told stories of the ways she is *"lucky"*, referring several times to the fact that Elizabeth *"didn't suffer... and I have to be thankful for that"*. It seemed that Jane works hard to maintain this narrative: *"I have*

to keep saying, Lizzie didn't suffer" and there was a sense that despite her perseverance, Jane's grief might easily become overwhelming again: *"I know that I would fall apart if I didn't fill my head with other things"*.

Jane's reference to people disliking those *"drowning in sorrow"* connects to societal discomfort regarding bereaved people, which was a prominent theme in Jane's story: *"society, perhaps the British society, more than some others... just can't cope with death"*; *"how society treats you, is something you have to cope with... people are just not comfortable"*. There were points in Jane's story when she demonstrated conforming to societal expectations: *"why should I burden people? I don't do that"*. However, at other times, Jane implied that this can take its toll: *"the majority of people will never know how upset I can be... and you sometimes get weary of that"*. This might have been reflected in the interview as Jane's emotions often seemed to fluctuate from controlled to uncontrolled, and on occasion, I as the interviewer changed the subject or offered reassurance when Jane became upset, perhaps inadvertently mirroring society's discomfort around grief.

4.2.3 David's Story

David is 60-years-old and he and his wife have three children. Their second child, Megan, was born with life-limiting health problems which led to her dying suddenly at home five years ago, when she was in her early 20s.

David told a story of the *"catastrophic"* loss of a daughter who was *"like my best friend"*. David explained that he was Megan's *"primary carer"* and so *"there was very rarely a time when we weren't together"*, emphasising the magnitude of his loss and added to when David said: *"it (grief) doesn't go away. You don't have somebody in your life, who you've looked after on a daily basis... it doesn't go away"*. David's

story of his close relationship with Megan may have been particularly important to tell given stereotypes regarding the male parental role (Anderson & Hamilton, 2005; Valiquette-Tessier et al., 2019), as well as societal assumptions that bereaved fathers' grief is less significant than that of bereaved mothers (Jones et al., 2019; Lang et al., 2011).

David continued a story of enduring grief which challenged the idea of grief being finite or linear: *"stages, whatever you want to call them, well for me, I didn't have any... and what happens at the end of it, are you supposed to feel normal again?... Because when this happens to you, you've got to find a new normal, nothing's the same again"*. David's use of the second person may address outsider audiences (e.g. professionals, academics or broader society), possibly some of which I represented. David told stories of his friends not understanding the ongoing nature of his grief, saying that over time *"the subject of Megan fell away"* and *"to them it's an eternity ago"*. David linked a story of his friends not initiating conversations about his loss to societal discourses about gender: *"men don't talk about how they feel... especially not to other men"*. David often seemed to challenge this narrative: *"I'm a bit more blunt when I'm talking to people in terms of my feelings"*; *"I want to engage with (my friends) especially if it's things about how you feel"*. This story suggested a change born out of grief, which was reflected in David's interview as he often referred to emotions, and at the beginning when I said that David could choose not to answer any questions he immediately said *"no, I'm open about it"*, potentially reflecting his desire to talk about his grief and not recreate his experiences of people *"dancing around the subject"*.

David told stories of a peer support group providing an ongoing *"opportunity to discuss (Megan) and remember her"*, and he emphasised the continued importance

of this, describing the group as *“worth gold”* and something he values *“very, very, very greatly”*. David told stories about learning through attendance at the group *“that everybody does (grief) in their own timeframe... what’s right for one person is not right for another”*; *“it’s about doing what’s important to you”* and said that over time he has gotten *“better at understanding... I’ve got more understanding of where I am”*. This story might suggest the development of a non-judgemental and compassionate view of grief over time, which has possibly facilitated David’s coping.

4.2.4 Charlotte’s Story

Charlotte is 45-years-old and ten years ago, her son Noah died of sudden infant death syndrome (SIDS) when he was less than 6-months-old. Charlotte and her husband have three surviving children, two who were born before Noah and one who was born around a year after he died.

Charlotte told a story of grief that was very visceral, and included lots of metaphors and rich descriptions related to bodily sensations. Charlotte referred to the *“physical pain”* she felt when Noah died: *“I couldn’t even walk, because I was in so much pain”*. Charlotte described her body as a *“pressure cooker”*, saying that for the first few years of grief she had to *“let the pressure and steam out... multiple times a day”* such as by *“talking about (Noah), or crying or having a freak out”*. Charlotte said that even now, at the time of anniversaries and milestones *“I feel a looming pressure... it’s the pressure cooker that builds up”*. Charlotte’s description of embodied grief may link to the physical experience of pregnancy, birth and mothering of an infant, emphasised when she said: *“your children... they’re your DNA... when they die... you change on a cellular level, and that change stays with you until the day that you die”*. This communicates the gravity and permanence of

Charlotte's loss, again alluding to a strong and physical maternal bond and possibly connecting with the notion that trauma is held within ones' body (van der Kolk, 2014).

A story of maternal bonds continued when Charlotte spoke about her surviving children. Charlotte said that in her early grief *"I was completely immersed in my children"*. Charlotte described getting pregnant in the months following Noah's death because *"I knew that... we needed to do that. It was like a kind of animal urge... a survival mechanism"*. Charlotte spoke about how her bonds with her surviving children motivated her to cope with grief: *"I think the things that changed me were... being involved with my children and understanding them"*; *"If I hadn't had (my youngest) and my other two kids, I don't know how..."*. Charlotte also described a change in priorities: *"work... didn't really mean that much to me anymore, and I really just wanted to be with my family"*; *"I'm probably happier with small... I like things personal, I'm very, very family orientated"*.

The narrative of Charlotte being a mother who prioritises her children might be important for her to communicate, particularly as she described experiencing *"terrible guilt"* in relation to Noah's death *"because he was wearing this quite thick... fluffy thing, that I got obsessed that I should have taken off"* despite the fact that *"of course the post-mortem said there was no sign of suffocation"*. This narrative of guilt might be influenced by historical mother-blaming discourses and SIDS-related stigma (Brännström, 2014; Cowgill, 2018). Charlotte acknowledged that her guilt *"is still there, and I think that's the real stubborn one... it's a real gremlin that lurks and could just become quite virulent if you're not careful"*. It was unclear how Charlotte is *"careful"* regarding her guilt, but it is possible that the previously described narrative of Charlotte prioritising her surviving children is important in helping her manage this.

4.2.5 Fiona's Story

Fiona is 55-years-old and has four children with her partner Ruth. Ten years ago, their second child William died in a hospice following a period of illness, when he was less than 5-years-old. Fiona and Ruth's two youngest children were born after William died.

Fiona began by describing William as *"such a sweetie"*, however did not share much more detail about him or his life, possibly reflective of the fact that Fiona has *"never totally reached the point"* of being able to *"access the happy memories... it's still too kind of intermingled with grief and loss for me"*. Fiona spoke about allowing herself *"little peeps"* into memories or thoughts about William, and described these as *"little sort of dipping in, private memories"*.

A story of Fiona's grief as *"private"* continued with her explaining that she has a *"very rich inner life"* that she isn't *"sure that people would know"* about. Fiona described feeling *"utterly altered"* by William's death, but told a story of this change being internal and not necessarily noticed by others: *"it is a very isolating experience, grief, and a lot of it is internal. And a lot of people don't want to... acknowledge that you are different as a result of it"*. Fiona spoke about this internal change when she told a story of accessing *"the dark side"* from which *"there is no going back from"* and explained how William's death *"unleash(ed) a different sort of understanding of the world"* in that she can now *"see the world for how difficult and complex it is"*. Fiona went on to say that this new perspective has *"definitely affected light-heartedness, but definitely brought me into being more present"* and said she feels *"more reflective"* and *"creative"* as a result. This contrasted with Fiona's description of people who are not bereaved and have responded unhelpfully to hearing of William's death: *"they don't have that level of soul really"; "the emotional depth or..."*

imagination to know (what it's like)". Despite this, Fiona reasoned "would I trade the kind of the self-awareness and... the learning through all of this? Yeah, yeah, I'd trade all of that. I'd rather be ignorant".

Fiona's narrative featured several rhetorical questions, such as illustrated in the last quote, giving a sense that she was weighing things up as she spoke: *"I don't know if people do think of him, and does it matter now as much? I don't know, because he's ours".* This sense was added to by Fiona's frequent use of the words *"but then"*, for example *"I'm a bit more private, which is probably not really how I'd like to be. But then... does that matter?"; "if I could go back to who I was, then I would... but then, I'd also want what I've got now".* This style of narrating may reflect Fiona's *"reflective"* nature, as it gave the impression that she was thinking aloud or in conversation with herself. It also gave the impression of multiple truths or *"duality"* which Fiona herself named, saying she can experience the *"coexistence of absolute agony and joy"* and that *"there is this duality I can move in... on a daily basis, and that's okay".*

4.2.6 Kath's Story

Kath is 60-years-old and she and her husband have two children, the eldest of whom, Imogen, was born with a life-limiting condition. Fifteen years ago, Imogen died in a hospice when she was less than 10-years-old.

Kath told a story of grief that began prior to Imogen's death, when Imogen received a life-limiting diagnosis as a baby, described by Kath as *"the worst moment, and really where the story starts"*. It seemed important to Kath to tell this part of her story, emphasised when she said: *"that bit of the story... is quite crucial... so that's why I'm telling you this bit"*, possibly because this is when her *"grief started"*. Kath

went on to tell a story of coming to terms with Imogen's prognosis: *"living with her knowing she would die is an excruciating and catastrophic way to live your life, but... every moment becomes full... we just lived fully in the moment... we adored every single cell of that girl"*. A narrative of doing all that she could for Imogen during her life seemed important for Kath to communicate, added to when she said *"we did everything for her"* and *"the whole thing was looking after our child in the best way we possibly could"*.

Imogen felt very present in Kath's interview, for example Kath would sometimes look at or refer to photographs of her in the room, and often spoke about Imogen in the present tense: *"she is an extraordinary being"; "she shows me the way of life, she really does"*. This implied an ongoing relationship which Kath spoke about more directly, telling a story of how *"in those early months and years I couldn't find Imogen"* and that *"the continuing relationship with Imogen, was something I had to find"*. Kath described herself as now *"living in a different world, where she lives with me"*. This narrative aligns with a continuing bonds theory of grief (Klass et al., 1996) which Kath directly named at one point, suggesting that her narrative has been influenced by this theory.

Kath's story often included reference to academic theory, as well as non-academic writing and poetry, which seemed to reflect how she has made sense of her experiences, through resonating with literature: *"from the very beginning, I knew... if I was gonna survive this grief and not die of pain, I had to understand it. So... I just read anything I could get my hands on"*. In addition, Kath explained that as she knew Imogen *"was going to die"*, she *"was reading all the loss books"* prior to Imogen's death, but that some of the things she thought she knew about grief turned out to be *"rubbish... it took the death of my child to realise what it's really like"*, and

that nothing could “*prepare*” her. This implies a disconnect between theory and reality, possibly spoken to an audience of researchers or clinicians (which I may have represented).

4.2.7 Sally’s Story

Sally is 60-years-old and has four children, the youngest of whom, Poppy, was born with a number of health problems and died 20 years ago in hospital when she was less than 5-years-old. Sally was in a relationship with Poppy’s father at the time but they have since separated.

Sally told a chronological story which started on the day of Poppy’s birth, when Sally felt a “*dreadful feeling of foreboding*”; “*I just knew there was something*”. Poppy was born with complex health needs and “*spent so much of her life in hospital*” with the family making frequent trips “*back and forth*”. This was reflected in Sally’s story of Poppy’s life which centred around the ups and downs of her health and was often set in hospital: “*she had the surgery and obviously she was in the intensive care unit... eventually she got taken up to the other ward, which meant that she was on the mend*”.

Sally continued a story of intuitively knowing that something was wrong with her child: “*it seemed to me there was something odd*”; “*(the doctor) just would not listen to me... but I was like ‘oh my God, I knew it. I knew it’*”. Sally told a story of Poppy’s health further deteriorating and “*suddenly*” experiencing “*complete clarity that it wasn’t right to keep on putting her through so much*”, leading to Sally stopping Poppy’s treatment which she communicated was “*the right decision for Poppy*”. The story of Poppy’s life positions Sally as a mother who trusted her instincts and did the best she could for her child. This seemed important for Sally to communicate and

may be influenced by societal discourses around what it means to be a 'good parent', particularly to an unwell or dying child (Hinds et al., 2009). Around half of the interview time was spent discussing Poppy's life – mainly her health decline and eventual death – further signifying the importance of this story in Sally's grief narrative.

Sally said that when Poppy died, she felt "*exhausted, from the years of constant care, backwards and forwards, and grief is exhausting as well, so I just felt so tired*". Sally described her initial grief as "*dreadful*" but proceeded with a story of progress: "*slowly but surely... a change happens, you don't get better, but something definitely shifts*". She described over time experiencing "*a little bit more feeling of freedom*" and said that now "*I'm not grieving for Poppy anymore... I miss her like I said, I wish she was here, but it's not the same*"; "*the loss is still there, but there's so much more going on in life*".

Sally described a process of learning as a result of her experience of bereavement: "*I think for me, grief has been a learning process... it will be a whole rest of my life learning process*". Sally sometimes seemed to communicate this learning to an audience of other bereaved parents (possibly those earlier on in their bereavement journey), using the second person and giving the sense of imparting hope and wisdom: "*you have to fill your life with other things, that's what helps*"; "*don't give up, never give up... your pain will bring you to a better place eventually, it really will*".

4.2.8 Teresa's Story

Teresa is 70-years-old and has two daughters with her husband. Twenty years ago, Teresa's youngest daughter Rachel died suddenly at her home following a short period of illness, when she was in her mid-20s.

Teresa told a story of Rachel's death as wholly unexpected: *"I only spoke to her the day before"; "it never occurred to me that she was even ill"*. When Rachel died, it therefore left Teresa in an *"absolute state of shock... I couldn't take it all in"*. The story of Teresa's grief continued in a mostly chronological way, although she also said *"the timeline is impossible to say"* and *"I can't even say the enormity of it"*, suggesting it was hard to explain her grief to me.

Teresa told a story of grief that has decreased in its *"rawness"* but has not gone away: *"the rawness, that we all feel for the first x amount of months or years, that has decreased... (but) I don't think it will get any less, I mean, she's always gonna be there"*. Here Teresa's use of *"we all"* seems to refer to bereaved parents as a collective, which was prominent throughout her account: *"we recognise as bereaved parents that a lot of people don't know what to say to us"*. Teresa's story often constructed a notion of bereaved parents as an 'in-group', who have *"this massive understanding"* of each other, contrasting with Teresa's stories regarding the rest of society: *"how can you understand something that you haven't experienced, you can't, I think it's asking the impossible really"*. Teresa named attending a peer support group as *"the thing that's helped me the most"* and spoke about how when with other bereaved parents she feels a *"feeling of relief, that 'ah, thank goodness, I've come home, I'm with people who understand'"*.

Connecting to this narrative, in this interview more so than others my outsider researcher status appeared significant, highlighted at times by Teresa: *"I don't suppose you've got any kids"; "you probably wake up and think... life is good"*. Teresa also took more interest than other participants in the audience of this thesis, asking who would read it, and proceeding to address "professionals" in her storytelling: *"the thing I'd say to professionals is... don't minimise grief... and don't give advice, listen"*. I wondered if I was included in the audience of "professionals", particularly as Teresa often spoke using the second person: *"it's as bad as you think it is multiplied by a million"*. Teresa spoke frequently about how important it is that *"people really listen"* to bereaved parents, possibly suggesting that she has not felt heard by others in the past. This connected to stories told by Teresa, who described her early grief as a *"hot potato"* that she felt *"desperate"* to talk about, but others often *"didn't want to bring (Rachel) up"*. At times Teresa seemed to think that I might not be willing to listen to her story: *"sorry I will stop... you haven't got that long"; "you must be fed up sat here listening to me"*, perhaps indicating the audiences that I represented to Teresa, i.e. society or others that have made her feel silenced.

4.3 Collective Stories

Following the analysis of individual accounts, data was analysed collectively. Throughout my reading and analysis of the individual accounts, notes were taken regarding general themes and points of connection across participants' stories. One particular point of connection I noticed was that a number of parents used metaphor related to landscapes in their stories, such as this quote from Kath:

Kath: *"When you're walking landscapes, you don't know how far you've come, until you look over your shoulder, and then you see what were massive"*

mountains recede into sort of undulating hills, that to me is a metaphor for my grief. It's like... look at all the ground I've covered"

I re-read each participants' transcript and made note of the ways landscape metaphor appeared in each account, compiling a list of quotes. Inspired by participants' use of metaphor, I decided to map out a visual diagram (Figure 2), which I conceptualised as a journey through the 'landscape' of bereaved parents' grief. The different stages of this journey went on to form my collective stories, which I further refined and also broke down into further sub-stories, informed by my notes regarding themes and patterns across participants' accounts. The final stories and sub-stories are outlined in Table 10.

As can be seen in Figure 2, the parents' journey begins before the children's deaths, in a lush landscape ('Before the Fall'), which is hit by a disaster (the child's death – 'Devastation Day'). Parents initially navigate 'Treacherous Terrain' (initial grief, described as feeling non-survivable) before moving into 'Flat Terrain' (later grief, described as sparse and permanent). Parents tell stories of adapting to their surroundings over time aided by the 'Oasis in the Desert' of peer support. Gradually there is evidence of new life growing in the landscape ('Learning to Live in New Surroundings'), but parents communicate that this does not replace their old world, which they continue to yearn for. Throughout each part of this journey, I will draw attention to the stories told by participants (illustrated with quotes), and how these connect to each other and to previous literature.

Figure 2

Illustration of Collective Stories

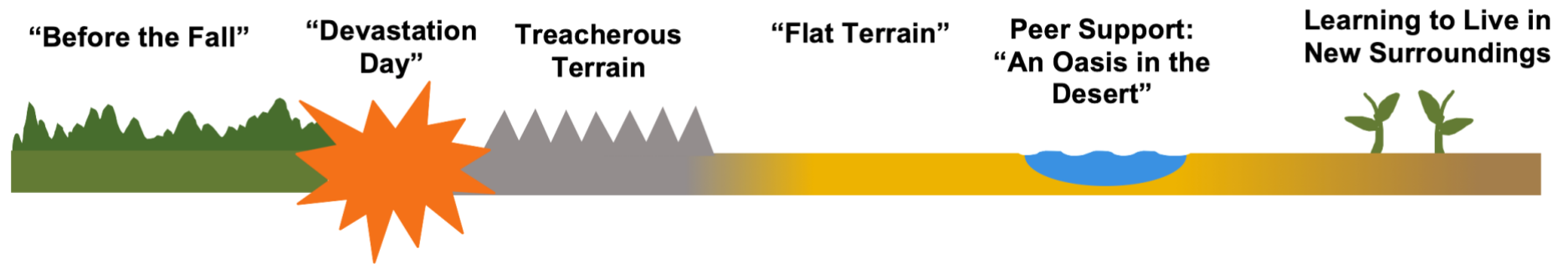


Table 10

Collective Stories and Sub-Stories

Stories	Description of Stories	Sub-Stories
“Before the fall”	Stories of life before death of child	<i>“We had a very happy life”</i> <i>“Never in a million years did I think that would happen to me”</i>
“Devastation Day”	Stories of child’s death	
Treacherous Terrain	Stories of early grief	<i>“Your world is never ever going to be the same again”</i> <i>“You’re totally at the mercy of your emotions”</i> <i>“How the hell am I gonna survive this?”</i> Needing people to <i>“bear witness to the grief”</i>
“Flat Terrain”	Stories of later grief	<i>“The expanse of grief feels never-ending”</i> <i>“I put on an outfit to be able to go out and be normal”</i> <i>“Trip wires”</i>
“An Oasis in the Desert”	Stories of peer support	
Learning to Live in New Surroundings	Stories of surviving and growing post-loss	<i>“It gets better but it doesn’t get better”</i> <i>“I have to be thankful”</i> <i>“My child who has died is still present in my world”</i> <i>“You have to fill your life with other things”</i> <i>“Pain is hard but it’s also learning”</i>

4.3.1 “Before the Fall”

This story encompasses parents' accounts of life before the death of their child, including sub-stories of happy memories (“*We had a very happy life*”) and feeling totally unprepared for the child's death (“*Never in a million years did I think that would happen to me*”).

4.3.1.1 “We had a very happy life”

All participants began their accounts in the past, telling a chronological story that started at their child's birth or younger years. This orientated the audience to the story's context (Labov, 1972), and seemed to communicate children's lives as ‘happy’ and ‘normal’. Most participants told stories of their children's positive qualities:

Alison: “*He was a lovely boy, very popular, had a lot of friends, as I'm sure everyone says, but he did*”

Fiona: “*He was such a little sweetie, he really was*”

These examples use emphasis (“*but he did*” and “*he really was*”) to stress that what is being said about the child is true. The stories about children's lives appeared to be influenced by their cause of death, for example four participants whose children died of health-related causes (Charlotte, David, Fiona and Sally) used the phrase “*really well*” to describe their children:

Charlotte: “*He was really well, really, really well... very healthy, very fine*”

Sally: “*She was just amazing, like, really, really well*”

Meanwhile Jane and Alison, whose children died following accidents, said respectively that their children had “*never been happier*” and were “*in a really good*

place” at the time of their deaths. These stories contain a great deal of certainty, created through words such as “*really*”, “*very*” and “*never*” as well as repetition, which creates contrast with later events and emphasises the shocking and tragic nature of each child’s death. It may have been important for participants to communicate that there were times when their children were “happy” and “well”, particularly as bereaved parents have described memories of such times as important in facilitating their coping (Fu et al., 2020; Saiki-Craighill, 2001) and the death of a child may at times silence or dominate the narrative of the child’s life (Hastings, 2000; Maple et al., 2009).

Stories of happy lives were further added to when participants spoke about their relationships with their children:

Jane: *“We obviously had a very good relationship with her”*

David: *“She was like my best friend, we were thick as thieves”*

Kath: *“We adored every single cell of that girl”*

Participants present these stories with much conviction, leaving no room for nuance and communicating to the audience that what is being said is significant and incontestable. Other participants illustrated their good relationships with their children by talking about spending time with them:

Alison: *“I loved going to see him... we just had those really nice times”*

Teresa: *“I used to go ‘round to her flat every week, and I’d get a nice fresh roasted chicken and a bottle of wine and I’d say ‘oh your flat looks nice’... just that whole thing”*

Kath: *“We had a very, very happy life, very happy... we went camping, we went to Spain... we were outdoors with her all the time”*

Sally: *“A lovely time of just being like a normal family”*

Participants' 'small stories' (Georgakopoulou, 2006) tell of the now treasured everyday and ordinary of family life, again told in an incontestable way through the use of intensifiers (“*very*” and “*really*”) and listing of details (Wiggins, 2017). This provides a 'before' narrative, capturing family life beyond the stories of the death and grief, which both interviewer and participant know are to come. Wooffitt (1992) highlights that when talking about out-of-the-ordinary events, people often begin by talking about normal, everyday experiences in order to create contrast, and it may be that participants communicating themselves as 'normal' was important in order to further emphasise how shocking and unjust the events that followed were, as well as to provide the 'before' story with credibility and substance to allow it to stand against the force of the story to come.

Overall, this sub-story positions participants as 'good parents', likely influenced by societal and cultural discourses about parenting (Lansford, 2022; Pedersen, 2012) including the assumption that parents are responsible for their child's happiness and wellbeing (Richardson et al., 2014; Stearns, 2019). This narrative may be influenced by audiences including myself as a researcher and trainee psychologist, and imagined audiences of professionals or the general public. The positioning of oneself as a 'good parent' may be important in coping with grief, particularly given that bereaved parents can report prolonged feelings of guilt and regret (Fu et al, 2020; Wheeler, 2001).

4.3.1.2 “Never in a million years did I think that would happen to me”

All participants told stories of the time when they were unaware that their child would die. Alison described herself as having “*two lives... before and after*” and

Fiona described the time before her son's death as *"before the fall"*. This language emphasises the stark contrast between participants' previous and current lives.

Participants spoke about how in their lives 'before', they were totally ignorant to the idea that their child could die:

Teresa: *"Never in a million years did I think that would happen to me"*

Fiona: *"Living in my world, where it never, ever occurred, and what a wonderful place to be really, it never occurred to me that a really bad thing - it always happened to other people... it wasn't going to be my story"*

These stories use extreme language (*"never ever"* and *"never in a million years"*) to communicate total unawareness, which gives the impression of parents' life expectations or schemas¹⁴ being completely shattered when their child died. Fiona's inference to living in a different *"world"* and having a different *"story"* imply a life totally disrupted by loss.

Three parents had children who were born with complex health problems, however despite this Sally said she *"never really believed"* her child would die, and David described believing that his child was *"indestructible"*, emphasising the shocking nature of their losses. In contrast, Kath explained that her daughter's prognosis meant that *"it was unequivocal that she was gonna die"*, and described the *"diagnosis day"* as the point at which her grief began. This is suggestive of anticipatory grief¹⁵ which bereaved parents in previous studies have also described (Higgs et al., 2016; Snaman et al., 2016). Despite this, Kath communicated that: *"even though we knew she wasn't gonna live, it was just the same"; "you cannot*

¹⁴ Schema are cognitive structures that individuals hold to organise knowledge about others, themselves and the world, which may be disrupted by traumatic events (Janoff-Bulman, 1992).

¹⁵ Anticipatory grief is a concept first named by Lindemann (1944) to describe the experience of grief prior to someone's death, when their death is probable or impending.

prepare". This connects to previous research which has found similarity between bereaved parents' experiences regardless of the circumstances of their loss (Calderwood & Alberton, 2023; Tan & Ketola, 2013).

4.3.2 "Devastation Day"

Across the accounts, participants described the death of their child as a catastrophic and life-altering event. In line with findings of previous research (Abdel Razeq & Al-Gamal, 2018; Yamazaki, 2010), most participants described the events building up to the moment they learnt of or witnessed their child's death in very vivid detail:

Alison: "I remember getting my make-up on, 'cause it was a really hot day, it was June, and it was a really hot day... and then I went to get the bins. Then I got my make-up on, and I went downstairs, and I went to put the bins out, because it was a Monday"

Charlotte: "It was really cold, and it was really dark, because it's, you know, that time of year, so it was dark... and the kids had all these toys, and they wanted us to put batteries in these toys... and we were putting batteries in the toys, and getting their toys working"

These stories include repetition, suggestive of a fragmented narrative¹⁶, as well as specific details including sensory information, all of which is associated with the recall of traumatic memories (Crespo & Fernández-Lansac, 2016; van der Kolk & Fisler, 1995). The accounts describe everyday events in detail, which creates the sense of a 'normal' day, about to be largely disrupted by a life-altering event.

¹⁶ Literature suggests that traumatic events can lead to fragmented narratives which may include repetition or be disorganised in terms of coherence or time (Foa et al., 1995; Halligan et al., 2003).

Participants used metaphoric language to describe their child's death, often related to natural disaster or the world ending:

Jane: *"Our world fell apart... our world shattered"*

Fiona: *"It felt like we were in this maelstrom kind of descent into hell"*

Teresa: *"I call it devastation day... it's like your house is built on these solid foundations, and all of a sudden... a bit like an earthquake I suppose, they just get blown up... and your whole house crumbles"*

Kath: *"Your world is decimated inside and out... it's like the tectonic plates of the earth shattering"*

The use of metaphor can help to communicate emotions and experiences that are abstract or intangible (Lakoff & Johnson, 1980). By likening their child's death to a physical disaster, parents are able to communicate the magnitude of their loss to an outsider audience. These metaphors create an impression of huge and irreparable damage, which connects to bereaved parents' reports in previous studies regarding the enormity and permanence of their loss (Malkinson & Bar-Tur, 2005; Tan & Ketola, 2013). This story particularly chimes with research by Feigelman et al. (2020), who described the death of a parent's child as "cataclysmic", labelled as "the crash" (p.633).

4.3.3 Treacherous Terrain

Building on from the previous story, participants' accounts of their early grief constructed a story of having to survive in a world permanently altered by disaster. This aligns with the findings of Malkinson and Bar-Tur (2005) who described how initially parents experience "acute sorrow" as if responding to "a disaster, an earthquake, where a person finds they are helpless" (p.112). Participants' stories

drew parallels with navigating a landscape that was dangerous and unpredictable, captured by Kath:

Kath: *"The landscape is irrevocably changed and somehow we have to get used to that new land"; "there's no stable place, you're completely churned up all the time... you land for a time... but you just hit the next bit of surf, the tide's gone out, you're flung onto another"*

Participants told stories of realising the enormity of the damage to their world, experiencing intense and overwhelming emotions, having to find ways to survive and needing support from others to manage, all summarised in the following sub-stories.

4.3.3.1 "Your world is never ever going to be the same again"

Across the accounts, participants described initially finding it hard to believe what had happened to them, or feeling disconnected from reality:

David: *"Days of just not being, not registering, not really believing it"*

Teresa: *"I felt as if everything was unreal... this couldn't be true"*

This is consistent with previous literature which has described parents entering a 'fog' in the immediate aftermath of their child's death (Calderwood & Alberton, 2023; Kachoyeanos & Selder, 1993). This may link with the aforementioned fragmenting nature of traumatic memories and thus loss of coherence in traumatic narratives (Brewin, 2016), and may explain why some participants' narratives of their grief initially seemed vague or distant. For example, Teresa described the first weeks of her grief as a *"blur"* and both Alison and Charlotte acknowledged that there was a lot they couldn't remember about their early grief.

Participants told stories of becoming aware of what had happened to them, emphasising a realisation of permanent change:

Kath: *"Your world is never ever going to be the same again"*

Fiona: *"It was... mind explodingly difficult really... it's like you're through the looking glass, I've passed into this world, and I can't go back"; "I knew that I had been utterly altered, and that I would never be the same again"*

Charlotte: *"It's like I've just taken a pill, and I can't un-take it. It's like that's me, forever"*

Reference to one's entire 'world' being impacted may help participants to communicate the gravity of their loss, and connects with previous descriptions of the child's death as a disaster. Participants' uses of the words "never" and "forever" communicate the absoluteness of their narratives. These stories align with findings of previous research that have described the grief process as never-ending (Calderwood & Alberton, 2023; Malkinson & Bar-Tur, 2005) and this may have been important for participants to communicate, particularly given reports that bereaved parents can feel that the permanence of their grief is not understood by others (Dutta et al., 2020; Feigelman et al., 2020).

4.3.3.2 "You're totally at the mercy of your emotions"

Participants told stories of experiencing intense, overwhelming and unpredictable emotions in the wake of their child's death:

Teresa: *"Imagine it's raining down all these different emotions, all coming down on you, and you've got this little umbrella and you're trying to dodge all these emotions, and it's shock, anger, anxiety, there's fear, there's sadness, there's sorrow"*

Charlotte: *"You're totally at the mercy of your emotions"*

Teresa's use of three-part lists (Wiggins, 2017) and Charlotte's use of the word "totally", help to communicate the severity of emotional impact, consistent with reports in literature that bereaved parents' emotions are most intense in their early grief (Abdel Razeq & Al-Gamal, 2018; Tan & Ketola, 2013). Almost all parents described feeling "pain":

Fiona: *"the white heat of the pain... that absolute white heat of intensity"*

Teresa: *"the pain is excruciating"*

Charlotte: *"I was in so much pain... pain in my heart, pain in my shoulders, just pain"*

These examples emphasise the severity of parents' distress and suggest somatised grief, connecting with reports from bereaved parents in previous literature (Lang et al., 2011; Malkinson & Bar-Tur, 2005) as well as Alison who likened her initial grief to an "illness". Other participants spoke about experiencing feelings that were hard to articulate:

Kath: *"I don't even know how to describe it to you, impossible to describe the pain I was feeling"*

Charlotte: *"I don't think I can really put it into words, it's beyond shock"*

Teresa: *"I can't even say the enormity of it"*

These accounts communicate feelings that are hard to justly capture with language, perhaps particularly important for parents to highlight to both me and other non-bereaved audiences, with an implication that this experience can only be understood by those who have encountered it.

4.3.3.3 “How the hell am I gonna survive this?”

Participants told stories of experiencing initial grief that was so severe they thought they would not survive it:

Sally: *“You just think, how the hell am I gonna survive this? How am I gonna get through this? Will I get through this?”*

Kath: *“Like, living in a world where I thought, I will not survive. I’m gonna die. I’m gonna die of pain”*

The reference to survival along with participants’ uses of repetition emphasise the level of distress described, in line with previous research which has found that bereaved parents report their initial grief as feeling non-survivable (Snaman et al., 2016; Tan & Ketola, 2013). Participants described how their efforts to survive took up all of their time:

Charlotte: *“the job of surviving takes up 100% of your time... you are really occupied with just trying to get through each day”*

Kath: *“It was just about surviving really, mentally and physically, that was the first few years of grief... just surviving”*

These accounts are similar to descriptions by bereaved parents in previous research, for example *“I was crawling... trying to survive”* (Tan & Ketola, 2013, p.146) and *“you’re so engulfed in trying to breathe in and out every single day”* (Calderwood & Alberton, 2023, p.8). Participants told stories of reduced functioning, for example Teresa: *“I couldn’t do anything, I couldn’t go out anywhere... I just couldn’t see anything outside of ‘my world’s fallen apart”*. Sally also spoke about being unable to do *“anything”*, creating emphasis and connecting with research findings regarding

bereaved parents experiencing hypoactivity in early grief (Calderwood & Alberton, 2023; Malkinson & Bar-Tur, 2005).

Some participants described a process of trying to survive by searching for answers or guidance:

Kath: *"I knew... if I was gonna survive this grief and not die of pain, I had to understand it"; "I was like a woman possessed, I read everything... where's the map, show me the way!"*

David: *"I was scrambling around for answers, trying to understand what happened"*

The use of language in these accounts ("*scrambling*" and "*possessed*") gives a sense of desperation and distress. This narrative connects with literature that suggests that bereaved parents initially seek answers to try and make sense of their loss (Ross et al., 2018; Wheeler, 2001), consistent with Neimeyer's (2001a) "meaning reconstruction" model of grief, which suggests that people must make sense of their bereavements in order to cope.

4.3.3.4 Needing people to "*bear witness to the grief*"

All participants told stories of difficulty being around people who couldn't "tolerate" their early grief, and a need to be around those who could. Most participants spoke about the helpfulness of others offering practical support and being present with them:

Charlotte: *"I didn't have to talk to them... I could just literally lie there... and they'd just come and... like, make sure there was food in the fridge"*

Alison: *"(My friend) used to cook us a meal every week... (another friend) just sat with me on the sofa... and we didn't really talk... she just put her arm around me"*

Kath: *"What are they gonna tell me?... I just need someone to be with me, and hold my hand, and make me lots and lots of tea"*

Fiona: *"(What was helpful was) people who kind of could bear witness to the grief and the pain, and who didn't want to make it better"*

These stories suggest parents valuing others not expecting much of them, and simply being 'alongside' them in their grief. These accounts align with research findings that bereaved people find it unhelpful when others give advice or try to 'fix' their problems (Cacciatore et al., 2021). These stories may challenge societal expectations that bereaved people should strive and be supported to 'recover' from their loss and 'move on' (Harris, 2010).

In contrast, most of the participants spoke about the fact that some of their friends *"didn't engage in the first place, because they don't know what to say"* (David). Across accounts, participants told stories of losing friendships as a result of this, for example Fiona explained that she *"shed"* people who did not support her in her early grief. Whilst participants described feeling disappointed and angered by others' responses, they also spoke about why they might have occurred:

Kath: *"(People's reactions) to child death are understandably horrific, because it is horrific. No-one can tolerate that idea... that's why people go weird, and can't look you in the face"*

Fiona: *"I think you represent something that terrifies them... I could really feel that you were the kind of manifestation of other people's horror"*

Jane: *"They were trying to cope with the shock of it all, and just didn't have the strength at that point to share, to support us"*

These stories suggest that parents have come to some understanding of others' responses over time. The story of others not being able to *"cope"* or *"tolerate"* death may connect with wider Western death-denying discourses (Kübler-Ross, 1975) and particularly the fact that a child's death goes against the natural order of life. Kath's comment that people *"can't look you in the face"* along with Fiona's description of others being *"terrified"* and experiencing *"horror"*, create a strong sense of alienation and stigmatisation, also communicated by David who said *"some people would cross the street to avoid you"*. Two participants specifically named British culture when explaining this experience: *"British society... just can't cope with death"* (Jane) and *"that British thing where we don't talk about our feelings"* (David). These stories connect to cultural narratives that White British people *"are not prone to wearing their emotions on their sleeves, and they are expected to bear suffering with a stiff upper lip"* (Walter, 1997, p.127), possibly suggesting that such discourses add to parents' experience of alienation.

4.3.4 "Flat Terrain"

This section explores participants' stories of later grief, which one participant likened to navigating a *"flat terrain"*. The following sub-stories describe participants' narratives regarding their grief changing over time but not disappearing, despite others' expectations that they should be 'feeling better'.

4.3.4.1 "The expanse of grief feels never-ending"

Participants described that as time went on, their emotions became less intense but this did not make their grief easier:

Kath: *"You think you're better but you're not, you're constantly treading in territory you don't understand"*

Charlotte: *"There's this kind of flat terrain you have to learn to navigate... instead of being in crisis mode, there's this permanence that kicks in that is really flattening, and the adrenaline that has kept you going starts to wane, and you're left with this weird story just going 'Where have they gone? They're not coming back, and I have to live with this dreaded grief for the rest of my life'... there's a sort of expectation that you should be feeling lighter, but weirdly, you're feeling heavier"*

Fiona: *"Sometimes I miss the white heat of it, because it was so simple"*

In the previous story of 'treacherous terrain' parents' only focus was survival, which may have been *"simpler"* and aided by increased *"adrenaline"*. Charlotte's description of a *"flat terrain"* evoked images in my mind of a vast desert, representing parents' realisation of the enormity and unending nature of their loss. This was also implied by Sally: *"the expanse of grief... it feels insurmountable and never-ending"* and Alison: *"sometimes I feel like there's a lot of life left without him"*.

The story of a "flat terrain" may connect with findings by Malkinson & Bar-Tur (2005), who describe that over time parents' grief moves from being an external "disaster" to an internalised part of their repertoire: "there is a kind of resignation that... grief has become part of life" (p.9). This description of grief was alluded to by Charlotte: *"It's bloody boring being bereaved... no-one tells you that, but... you feel so awful, you don't want to feel like this anymore... and you know why you're like this because you're heartbroken, but it is boring"*. Other parents described not being able to feel genuine happiness for years after their child died, and feeling surprised,

exhausted and frustrated with their apparent lack of progress. For example, Sally spoke about her grief going *“on and on, I couldn't believe it”*, and Teresa spoke about feeling *“trapped”* in her grief and feeling *“cross”* with herself for not feeling better a few years after her bereavement. Kath described hitting a *“bad patch in year two”* because *“you... get through year one, you think ‘pew I need a medal’, but they're still not there, it's like... ‘I've got through the first year where's my prize? Where is my child?...They're still dead, and I can't stand it”*.

This sub-story suggests grief that does not get better after the initial response, diverging from staged models of grief (e.g. Kübler-Ross, 1969), and also previous literature which has reported that bereaved parents describe significant progress 12-months after their bereavement (Abdel Razeq & Al-Gamal, 2018; Calderwood & Alberton, 2023; Saiki-Craighill, 2001; Ross et al., 2018). In addition, this may invite reflection on what is considered 'progress', as the participants in this study suggest that the reduction of intense emotions is not always experienced by them as 'progress', but instead a different challenge to endure. It may have been important for participants to communicate this in order to challenge others' or society's expectations about their grief trajectory.

4.3.4.2 *“I put on an outfit to be able to go out and be normal”*

In line with previous research (Alam et al., 2012; Calderwood & Alberton, 2023), most participants told stories of support from others reducing over time:

David: *“Friends were good initially, but then it's strange how quickly they'd fall away”*

Sally: *"Everyone just disappears... everyone just gets back on with their lives, which is of course natural, people have a life to live, but it's like they forget that you're going through this dreadful time"*

Continuing with the "flat terrain" metaphor, the reference to people 'falling away' or 'disappearing' may suggest a sparse and lonely landscape, with others assuming that now parents are on 'flat ground' they do not require support. Participants described how over time *"the rules apply"* again (Fiona), as they are expected to socialise and return to work. Participants told stories of finding this transition difficult to manage:

Teresa: *"We had to go to a wedding about 2 years after Rachel died... I said I'm not going, but (my husband) said we can't just not turn up. And, I did go in the end, but I cried the whole way through... I just cried about Rachel"*

Charlotte: *"Work can be really difficult... (you think) 'what am I doing? Why am I walking down this busy street? I need to get home, and be with their belongings'"*

Alison: *"I felt like I was putting on an act and then the minute I left work it all hit me, and I just used to be in a really bad way"*

These stories connect with research findings that have described social interactions creating pressure for bereaved parents (Fu et al. 2020, Saiki-Craighill, 2001), which might be influenced by Western societal expectations regarding returning to self-sufficiency and functioning post-bereavement (Harris, 2010; Walter, 2010), as well as psychiatric understandings of 'normal' vs 'pathological' grief and the existence of diagnoses such as "prolonged grief disorder" (American Psychiatric Association, 2022).

Participants told stories of a continuing disconnection between how others perceived them and how they felt inside:

Jane: *"The majority of people will never know how upset I can be... and you sometimes get weary of that"*

Alison: *"I feel like I put on an outfit to be able to go out and be normal"; "I do put on a bit of an act... I feel often that I'm not really me"*

David: *"(People ask how I am) and I'll be quite blunt and say well I'm not too good at the moment, I'm feeling pretty depressed. And sometimes people will say to you 'Oh why? What's wrong?', as if, well do you remember something happened to me five years ago? It, to them it's an eternity ago, to me it was yesterday."*

Fiona: *"(An acquaintance) said 'oh you're the same', and I said 'no I'm not... I look the same but I will never be the same'... and... actually I'm an utterly, completely, badly put together version of the person that I was, that is all I am really"*

These stories imply a tension caused by others perceiving parents as their 'old selves' and perhaps not recognising the gravity of the change they have undergone as a result of their loss. This suggests an incongruence between the way participants perceive themselves, and how they are perceived by others, which connects to narrative ideas that the 'self' is socially constructed and can be 'performed' relationally (Gergen, 2011; Somers, 1994). Alison and Jane both imply putting on an "act" of feeling better around others, whereas David and Fiona both talk of more directly letting people know that they are still grieving, suggesting that parents have different ways of responding to this incongruence. However, all stories connect in

communicating that this experience is ongoing and potentially burdensome for parents.

4.3.4.3 “Trip wires”

Despite parents no longer being in the “*white heat*” (Fiona) of their emotions, most of them explained that they continue to experience unexpected peaks of grief. Relating this to a metaphor of navigating terrain, it might be said that whilst parents are out of the constantly ‘treacherous’ land, they continue to occasionally stumble across hazards and dangers, described by Teresa as “*trip wires*”:

Teresa: “*the famous trip wires... when everything seems so acute*”

Teresa described not knowing when a “trip wire” is coming, and them being unpredictable and inconsistent in nature. Other parents described grief being triggered by specific reminders:

Jane: “*Anniversaries, birthdays, Christmas... the whole body is telling me ‘this is a bad time coming up’, and that’s as raw as it always has been actually*”

Sally: “*Her 10th anniversary, that was a terrible anniversary... it felt worse, as bad as the first*”; “*Christmas this year, I did really feel like I missed her more than I had for a long time... I was very tearful and felt I couldn’t bear it*”

In these examples, specific dates are named as “trip wires”, consistent with parents’ accounts in previous research (Entilli et al., 2021; Kachoyeanos & Selder, 1993).

This again challenges a finite, linear view of grief and may connect to the dual process model, with parents entering a ‘loss-orientated’ state at these times and experiencing their grief as more intrusive (Stroebe & Schut, 1999).

In contrast to intrusive experiences, some parents spoke about a need to “access” intense emotions:

David: *"If I need to cry about something... I know the places I can go, and the thoughts that I need to have to... bring me down to remembering all that"*

Fiona: *"I can so easily access the tears, and... the utter being gutted, but, it's less powerful"; "That absolute white heat of intensity, I think I can't access that, and I do miss it... there's a little bit of me that thinks 'oh I wish I could feel that again to reconnect' because I think then you end up a bit numb"*

These accounts both suggest a purposeful pursuit of emotion, possibly connecting to research findings by Fu et al. (2020) who described bereaved parents moving from "involuntary" to "voluntary" yearning for their child. Fiona describes her peaks of grief as not as intense as they used to be and, contrary to expectations, describes missing the intense emotion. This was possibly linked to a story in Fiona's account about emotion being a way of remaining connected to and "*honouring*" her child, and again this speaks to a non-linear and idiosyncratic understanding of grief.

4.3.5 "An Oasis in the Desert"

Across all accounts, and in line with previous research (Snaman et al., 2016; Sterling et al., 2022), participants spoke about the value of peer support from other bereaved parents, described by Teresa as "*an oasis in the desert*". Participants described finding relief in peers who could be "alongside" them:

Fiona: *"The opportunity to share that path that we were heading down with other people who were also heading down that path, you know, somewhere you really don't want to go. It's like, we will walk this path with you to nowhere... it's walking alongside you really"*

Kath: *"It's coming alongside each other, and the comfort, and the humour... but its good humour, 'cause it's terrible humour, and it's facing the horror, but we can say things you can't say to anybody outside that room"*

These stories connect with previously mentioned stories related to needing others to 'bear witness' to grief, and contrast with stories of having to put on an act around (non-bereaved) others, suggesting that other bereaved parents are able to face *"the horror"* and walk *"alongside"* each other. Across accounts, parents created contrast between wider society and peer support spaces:

Teresa: *"It was like having this great big boulder between me and the world. It was like a great big boulder, and the only time I felt that boulder was removed was when I was with other bereaved parents"*

Kath: *"You feel very isolated and very alienated, like you're from a different world, which you kind of are, but, there's very few people you can spend time with, and often its bereaved parents"*

The descriptions of feeling from a *"different world"* or separated from the world by a *"boulder"* construct a sense of alienation and emphasise the value of peer support in offering relief from this. These stories communicate a shared identity with other bereaved parents, which emerged across accounts:

Jane: *"You really only to me, have 100% understanding if you yourself have experienced it"*

Alison: *"it was that whole feeling which I think is very important for people like us is that, to be in a room with people who actually know and feel the same"*

Teresa: *"It's this need to be with people who understand it... how can you understand something that you haven't experienced?"*

Alison's reference to *"people like us"* was echoed by most parents who also used 'we' and 'us', referring to bereaved parents as a collective and emphasising a sense of belonging to a group. This further adds to a story of 'bereaved parent' as an in-group identity that I, and the non-bereaved audience(s) I represent, are unable to access or understand.

4.3.6 Learning to Live in New Surroundings

The following section focuses on the stories told by participants regarding how they have survived and grown post-bereavement, likened to adjusting to living in a new environment despite ongoing challenge and longing for ones' old 'world'.

4.3.6.1 *"It gets better, but it doesn't get better"*

Across the accounts, participants told stories of making progress, but in line with previous research (Snaman et al., 2016; Tan & Ketola, 2013), they were clear that their grief will never be fully resolved:

David: *"You're never gonna get over it, or move on, all you do is move to a different place... it doesn't go away, it just moves further down the track"*

Sally: *"It gets better but it doesn't get better"*

Jane: *"It changes, but the reality never goes away... and it's not gonna get any better"*

Participants' communication of the gravity of their loss may chime with research suggesting that parental bereavement is a uniquely devastating type of loss (Rando, 1985; Rosof, 1995), which was named by several participants, for example Alison: *"with a child, I think it's a very specific kind of pain"*. Across accounts, participants spoke about experiencing continued longing for their child:

Jane: *"Every day I'm missing her. There's something every day that I wish she was here for. So that hasn't changed"*

Fiona: *"The absence and longing is always a part of me and a part of my day"*

Alison: *"You know when you're homesick, you're desperately, desperately homesick. I can remember that as a kid when you went away and just wanted so much to be at home, and it's that feeling I feel a lot now. I just want to see him, I miss him. And that missing, just makes everything not comfortable"*

Alison's reference to feeling "*homesick*" might imply the loss of an old world or old life, consistent with participant's descriptions of their child's death as an earth-shattering disaster. Other participants also told stories related to this:

Teresa: *"I feel my life has changed, my whole world has changed"*

Kath: *"I now live in a different world, an altered world... I breathe different air"*

By talking about a change occurring to one's 'world', participants are able to communicate to an audience the magnitude and permanence of their grief. Other participants described a profound physical change to themselves, with Charlotte and Fiona both describing their DNA changing as a result of loss, and Kath and Fiona respectively describing their grief as a "*brain injury*" and "*brain damage*". This narrative may also connect to participants' sense of selves, suggesting participants perceive themselves as totally changed, which may differ from others' perceptions of them, or how their identity is socially constructed (Gergen, 2011).

Participants communicated that the idea of their grief being resolved was offensive or jarring to them, because it would insinuate they had forgotten their child:

Charlotte: *"The idea of (a point when your grief is) all gone... no bereaved parent ever wants that to happen, because that would mean their child is back there (points behind)"*

Kath: *"Grief and love they're exactly the same, they're intertwined, you're never gonna stop loving your child, so therefore you're never gonna stop grieving your child, this is what people don't get, it's like... are you gonna love your child any less? Are you gonna love your surviving child more than your child who's died because they've survived? No, you're not! It's illogical!"*

Kath referring to people 'not getting' the permanence of her grief was echoed by other participants as well as by bereaved parents in previous research (Calderwood & Alberton, 2023; Tan & Ketola, 2013), and these stories may have been communicated to a wider audience of society or those ignorant to parental bereavement.

Despite clearly communicating never 'getting over' their loss, parents did talk about ways they have grown or adjusted to their new life over time. This might be thought of as 'new life' growing in the parents' landscape. Parents' narratives may suggest that this new life has found ways to grow despite continued hostile surroundings, with stories emerging across narratives of survival 'against the odds':

Jane: *"We get on with life"; "(it's not easy) but it's fine because we're living"*

Teresa: *"You keep going, but you stagger and limp through life"*

Fiona: *"You just kind of put yourself back together, but what you put back together is a really kind of ill-fitting, badly fitting, version of the person that you were before"*

These narratives starkly contrast with parents' descriptions of their happy lives 'before the fall', aligning with research by Wheeler (2001) who noted that bereaved parents spoke with a "tone of resignation" with one parent voicing *"life goes on for us, but without its original brightness"* (p.57).

4.3.6.2 "I have to be thankful"

Despite communicating the permanence of their grief, participants were able to draw on positives in their lives, including reasons to be "thankful". Four parents (Alison, Charlotte, Jane and Teresa) described themselves as *"lucky"* because they had supportive friends or family. For some participants, feeling grateful was related to the cause of their child's death:

Kath: *"I actually feel lucky... I was able to be with my child when she died, and lots and lots of parents haven't had that"*

Jane *"Lizzie didn't suffer... and I have to be thankful for that"*

David: *"I'm glad she, it was the most painful thing for us to lose her very suddenly, but it was the kindest thing for her"*

In these examples, all parents communicate feeling thankful despite having different experiences of their child's death (Jane and David's daughters died suddenly whereas Kath's daughter died in a hospice). Alison spoke about noticing that bereaved parents often find reason to be grateful regardless of the circumstance of their child's death:

Alison: *"(My friend's) daughter died of cancer... and I said to (my husband) 'I can't imagine how they dealt with that week when they knew she was dying'... but then she said to me 'well I think it's so awful that you didn't get a chance to say goodbye'... so, I think people have to deal with it differently"*

This narrative is possibly indicative of coping with grief through sense-making, consistent with a meaning reconstruction model of grief (Neimeyer, 2001a), which suggests that bereaved people undergo a process of sense-making and 'benefit-finding', in order to adjust to living life post-bereavement. Fiona added to this narrative when she spoke about this process more directly:

Fiona: *"I had to sort of learn those skills of being really grateful, and having joy in what you've got rather than what you haven't got"*

This communicates gratitude as a 'skill' that must be practised, and might suggest that bereaved parents have to put effort into upholding their thankful narratives.

4.3.6.3 "My child who has died is still present in my world"

Across accounts, all participants described an ongoing relationship with their deceased child, consistent with previous research findings (Malkinson & Bar-Tur, 2005; Yamazaki, 2010). All participants spoke about continuing to regularly think and talk about their child as a way of keeping them present:

Teresa: *"I don't let her be the elephant in the room, I talk about her"*

Sally: *"I want my life to be to be and feel normal. And that means that my child who has died is still present in my world and I want to be able to talk about her and I want others to be able to talk about her without feeling uncomfortable"*

Here, Sally's reference to not wanting others to feel "*uncomfortable*" along with Teresa's use of the phrase "*elephant in the room*" both indicate there may be difficulty having these conversations with some people. Other participants echoed this and spoke about how valuable it was when other people did continue to talk about their children:

Jane: *"We reminisced about the kids when they were little and of course Lizzie was mentioned. And that was just magic"*

David: *"(it's helpful) when people want to know... and will talk to you about it and expand on that... it gives me the opportunity then to talk to about her, which I like to do"*

This suggests a process of parents keeping their child present through memory and conversation, as described by Alison: *"We keep him alive because we talk about him, we remember all the things he did"*.

Each parent told stories of the unique ways they maintain relationships with their children. Some parents spoke about continuing to talk to their children (Jane, Kath, Sally), visiting their children's gravesites (Jane, Alison) and keeping their child's belongings (David, Fiona). Alison spoke about getting a tattoo in memory of her child, Teresa about her family setting a space at the Christmas table for her deceased daughter, David shared that his daughters' toy bear *"escorts us everywhere we go... we can't go away without it"* and Sally said *"I buy little things for her... Christmas decorations... flowers"*. All parents said they have photographs of their children, which were clearly displayed in the homes of those interviewed face-to-face. Despite each parent having idiosyncratic ways of continuing a relationship with their child, all of them emphasised the importance of their child remaining present in their life:

Charlotte: *"I'm doing everything I can to deal with it, in the best way that I know for me, which is to bring him into my everyday life"*

Sally: *"She's just part of my life, she'll be part of my life 'til the day I die"*

This sub-story is consistent with a continuing bonds theory of grief (Klass et al., 1996), which emphasises the importance of an ongoing and life-long attachment to the deceased, in contrast to earlier understandings of grief (Freud, 1917; Bowlby & Parkes, 1970) which suggested that detachment was important for adjustment to loss.

4.3.6.4 “You have to fill your life with other things”

Across accounts, participants spoke about the importance of having things to “fill” their lives with:

Charlotte: *“You’ve got to find something that gives you a focus and a feeling of forward motion”*

Sally: *“I think you have to fill your life with other things and that’s what helps. It’s growing your world. And once your world grows it’s bigger... the loss is still there, but there’s so much more going on in life”*

Sally’s reference to “growing your world” aligns with Tonkin’s (1996) model of “growing around grief”, which suggests that an individual’s grief does not shrink or disappear, but that their life outside of grief grows bigger over time. Participants spoke about the ways they have invested in life outside of grief, with most naming surviving children as a source of motivation:

Alison: *“(My daughter) keeps me carrying on because I’ve got to, for her”*

Kath: *“(my son) has been an absolute god-send, because he showed us the way when we couldn’t find the way”; “he kept us going to be honest”*

These references to ‘keeping going’ suggest surviving despite hardship, connecting to previous stories around participants ‘getting on with life’ despite continuing to grieve. Bereaved parents in previous research have also named surviving children

as a source of strength (Alam et al., 2012; Tan & Ketola, 2013). Two parents (Fiona and Charlotte) spoke about finding motivation through conceiving further children which has also been reported by other bereaved parents (Abdel Razeq & Al-Gamal, 2018; Chen et al., 2019),

One participant (Jane) lost her only child, and explained that as a result she now volunteers for a charity working with children, because *“we need young people to keep us young”*. Jane spoke about keeping *“busy”* and said that: *“I know that I would fall apart if I didn't fill my head with other things”*. Other participants echoed this:

David: *“I run at running club, if I wasn't doing that for my mental health I don't know where I would be”*

Teresa: *“I think it's much healthier to be out, to be thinking about other people, to be interested in the world... if I spend a lot of time on my own, I don't feel fulfilled... so for me, having a timetable for my week and knowing I'm doing this and that, does help me”*

These stories suggest that bereaved parents have to actively distract themselves otherwise their grief could easily become overwhelming again. This connects to a dual process model of grief (Stroebe & Schut, 1999), which suggests that parents oscillate between a loss-orientated state (i.e. intrusion of grief) and a restoration-orientated state (i.e. distraction and attending to life changes).

4.3.6.5 *“Pain is hard but it's also learning”*

After a landscape is ravaged by disaster, new life can emerge over time that did not grow there previously, captured in this quote about forests recovering from natural disasters: *“As the landscape slowly regenerates, where trees once*

dominated, unique, diverse grasses, herbs and shrubs that aren't found in other stages of ecological development are flourishing, and ecological progress is clear" (Madren, 2012; para. 30).

In a similar way, whilst participants communicated that their lives were forever 'tainted' by grief, and that their old 'world' would never return, they also told stories of new growth, or positive changes to their lives as a result of their loss. Participants implied that this new growth did not compensate for or replace their loss but did help to make their grief easier to bear.

In line with previous research results (Calderwood & Alberton, 2023; Wheeler, 2001), participants spoke about a shift in perspective and prioritising the things that matter to them:

Charlotte: *"I don't really kind of stress out about the small things anymore. I'm much more, I suppose able to see what matters"*

Fiona: *"I do live much more in the moment and feel the utter joy of our kids, I really really do, because I kind of know how tomorrow it could all be different, and you only have what you have today"*

Kath: *"I realised the only important thing in life is the present moment".*

Other participants spoke about positive changes to their personality as a result of their loss, such as feeling "*stronger*" (Charlotte) and "*more confident*" (Sally), which has similarly been reported by parents in previous research (Dutta et al., 2020; Punaglom et al., 2022). Some participants said they felt more motivated to listen to or engage with other people following their bereavement:

Sally: *"I feel I'm a better person... I find like people come to me, they... can come and be honest and open up, I think they know that I'm a non-judgemental person and I will be patient and listen to what they have to say"*

Teresa: *"I think I've learnt even more, the value of active listening... I think, if you are able to listen to people, it does an awful lot of good, 'cause it did to me"*

David: *"I would (previously) prefer to be in the background... on the edge of the conversation, now I like to be in the centre, and engage... especially if it's things about how you feel and about mental health"*

These stories may have been strengthened by peer support, with several participants naming the value of listening and learning from other bereaved parents, and forming new friendships as a result (David: *"I've lost friends but I've also gained friends"*). Across accounts, participants spoke about learning who their *"real friends are"* (Alison), and *"cherishing"* (Fiona) these friendships as a result.

Overall, this sub-story aligns with findings related to bereaved parents experiencing post-traumatic growth over time (Engelkemeyer & Marwit, 2008; Waugh et al., 2018), captured in a quote by Sally:

Sally: *"Grief is a lifelong learning process. It's not just about being sad and devastated that your world got turned upside down, but... your pain will bring you to a better place eventually... it'll bring you to a different place... pain is hard, but it's also learning"*.

Chapter Five: Conclusions

5.1 Chapter Overview

In this chapter, I summarise the findings of this study, referring to the research aims and previous literature. I then discuss the study quality, clinical implications and suggestions for future research, before concluding with some final reflections.

5.2 Summary of Findings

This research aimed to explore the stories bereaved parents tell about their experiences of grief over time, and to consider what these stories might suggest about how they have adjusted to the death of their child.

The participants in this study told stories of life prior to their children's deaths which highlighted their good relationships with their children as well as the happiness and normality of their lives. Most participants told stories which communicated that they were totally unaware that their child would die. My interpretations of these stories were that they made it clear to the audience that the children were happy, loved and 'good', which emphasised the tragic and unjust nature of each child's death, and possibly communicated to an outsider audience that the death of one's child can happen to anyone. I wondered whether these stories were important in facilitating participants' coping, perhaps particularly in managing guilt, which is an emotion commonly reported by bereaved parents (Dyregrov & Dyregrov, 1999; Saiki-Craighill, 2001; Tan & Ketola, 2013), as well as allowing parents to remember and honour their child's life beyond the fact of their death. Previous research with bereaved parents has tended to focus on the time after the child's death, however this finding may chime with bereaved parents' reports of holding onto positive memories and meaning regarding their child's lives as a way to cope with their death (Feigelman et al., 2020; Fu et al., 2020; Saiki-Craighill, 2001).

Participants told stories which constructed their child's death as an earth-shattering disaster, and their stories of their early grief reflected this as they described trying to survive in a world that was irrevocably changed. These stories communicated the permanence and magnitude of parents' grief, which connects with previous research (Arnold & Gemma, 2008; Snaman et al., 2016; Tan & Ketola, 2013), and may be influenced by the fact that bereaved parents have reported that the longevity of their grief is often misunderstood by others (Calderwood & Alberton, 2023; Dutta et al., 2020; Feigelman et al., 2020). Participants told stories of needing others to be present and alongside them in their early grief, which contrasted with stories of people avoiding, ignoring or showing discomfort around them. Similar experiences have been reported by bereaved parents in previous research (Calderwood & Alberton, 2023; Feigelman et al., 2020; Kachoyeanos & Selder, 1993), however in this study participants described this experience occurring not only because others did not know what to say, but also because bereaved parents might represent something terrifying to others (i.e. mortality). This narrative constructed a strong sense of alienation, and might be influenced by Western discourses related to death denial (Kübler-Ross, 1975). Studies exploring British bereaved parents' experiences of grief over time are scarce, and some parents specifically named 'Britishness' when telling stories of others' discomfort, connecting with literature which suggests that compared to other cultures, British society expects grief to be a particularly private experience (Walter, 1997).

Participants' stories of their later grief were conceptualised as having to navigate a "*flat terrain*", which brought a new set of challenges to endure. Participants told stories of their emotions becoming less intense over time, which created new challenges, as adrenaline waned and they realised the permanence

and vastness of their grief. Participants spoke about difficulty in feeling less connected to their children, as they moved beyond a stage of a life all-consumed by grief, to a point of being expected to re-engage with their 'normal' routine again. The notion of this "flat terrain" experience was not evident in the SLR papers, and has important implications regarding what is considered 'progress' or 'recovery' for bereaved parents. Participants described returning to activity and feeling less intense emotion (likely considered by others as positive progress), but this bringing new hardship and in some cases, making them feel worse. This story may connect to non-linear models of grief such as the dual process model (Stroebe & Schut, 1999), however, here parents seem to communicate being in-between a loss-oriented or restoration-oriented state, with parents implying they felt neither connected enough to their child, or able to fully distract themselves.

Stories were told about other people assuming that as parents were now on 'flat ground', they did not need support anymore and had returned to their 'old selves'. This contrasted with parents feeling, as Fiona put it, like an "*utterly, completely, badly put together version*" of themselves, with stories told of social pressure, isolation and alienation. Some studies in the SLR described social situations initially causing pressure for bereaved parents (Fu et al., 2020; Ross et al., 2018; Saiki-Craighill, 2001), however the participants in this study implied that this experience was ongoing and they still felt the need to 'act' around others, which was not as clearly described in the SLR papers. Participants told stories of social pressure being alleviated when with other bereaved parents, and spoke about the value of peer support, which was also reported in most of the SLR papers (e.g. Fu et al., 2020; Sterling et al., 2022). Furthermore, in this study, participants' stories gave the sense of 'bereaved parent' as an identity – one that can cause feelings of

alienation but can also provide means of connection with those who share this identity. This alluded to a collective identity i.e. bereaved parents belonging to an 'in-group' that others (including myself) cannot access or understand.

Participants communicated that whilst they remain in the 'flat terrain', they have experienced some growth in their landscape over time. Participants described a need to 'fill' their lives with things other than grief and, in line with previous research (Alam et al., 2012; Chen et al., 2019; Entilli et al., 2021), told stories of engaging in hobbies, projects or socialising as well as focusing on their relationships with their surviving children in order to cope with their grief. This sub-story aligns with Tonkin's (1996) "growing around grief" model, which proposes that a bereaved individual's grief does not shrink, but rather their life outside grief grows over time. Participants implied that without distraction their grief could easily become overwhelming again, connecting with Stroebe and Shut's (1999) "dual process model", with participants balancing the intrusion of their grief with restoration-oriented coping. All participants communicated that keeping their child present in their life was key, as has been found in previous research (Alam et al., 2012; Malkinson & Bar-Tur, 2005; Punaglom et al., 2022). Each participant had idiosyncratic ways of achieving this, but the premise of an ongoing relationship with the deceased child was central, connecting with a "continuing bonds" model of bereavement (Klass et al., 1996) and challenging the notion of reaching a stage of 'moving on' from or 'letting go' of the deceased.

All participants told stories indicative of post-traumatic growth, for example sharing that they felt stronger, more able to see what was important in life, or that they were a 'better person' as a result of their loss. This connects with previous literature that describes post-traumatic growth in bereaved parents (Engelkemeyer &

Marwit, 2008; Waugh et al., 2018), as well as papers in the SLR which described evidence of post-traumatic growth in participants over time (Dutta et al, 2021; Entilli et al., 2021; Feigelman et al., 2020; Ross et al., 2018). In addition, all participants told stories of the ways in which they were fortunate, including feeling relative gratitude regarding their child's cause of death, or having supportive friends and family. These stories connect with Neimeyer's (2001a) "meaning reconstruction model" of grief which suggests that over time bereaved individuals go through processes of sense-making and identify 'benefits' or learnings that have occurred as a result of their loss.

Overall, participants communicated that whilst they had made some progress in adapting to their grief, their bereavement has permanently changed their 'world' and life will never be the same again. This is in line with SLR findings regarding the never-ending nature of parental grief, and deviates from staged or linear models of grief. This may have been particularly important for participants to communicate given societal misconceptions regarding grief (Harris, 2010). I conceptualised participants' grief as a landscape ravaged by a disaster, which shows signs of regrowth over time (including new life that did not grow there previously), but never returns to its previous state. It is important to note that my understanding of participants' grief will be shaped by my own context and lens as well as the limitations of this study, discussed more in the next section.

5.3 Quality Assessment

I used Tracy's (2010) eight "big tent" criteria for qualitative research to evaluate this study; this was the same approach used to assess the quality of papers in the SLR (Chapter 2).

5.3.1 Study Strengths

This research adds to the existing literature as research exploring bereaved parents' experiences of grief over time in a UK context, as well as using narrative methodologies, are scarce, and no such papers were identified in the SLR. Using narrative methodology allowed for individuals' stories to be presented intact, which has not been done in previous research and may be important given the SLR findings regarding the idiosyncratic nature of parental grief. Furthermore, by considering elements related to narrative structure and performance, this study may provide insight into how participants' stories about their experiences facilitate their coping with loss.

This study explored parents' stories of their grief, including stories of the time prior to their child's death, which adds to the literature given that most studies have chosen to explore bereaved parents' experiences from the time of the child's death onwards. Most of the parents interviewed commented that the interview had been a positive experience and that they had valued the chance to tell their story from the beginning until the present day, which is particularly relevant given the findings of this study that suggest that bereaved parents can feel silenced by society.

One of the weaknesses of the SLR papers was with regards to sincerity, with none of the papers acknowledging the researcher's position in relation to the research. In this study I considered my outsider researcher status and how this may have influenced the stories told by participants, aided by the social constructionist positioning of the research which considered stories as co-constructed between participants and various audiences. I have written in the first person to reflect this and have included frequent quotes from participants in my writing to increase the credibility of my findings. As highlighted in Chapter 3, it was not deemed appropriate

to member check my findings with participants given the research positioning, however steps have been taken to increase quality, including the use of supervisory and peer support spaces to check my transcript coding, interpretations and write-up, as well as the use of EbE input at various stages of the research design.

Overall, this study achieved its aims of exploring the stories told by bereaved parents about their grief over time, and considering what these stories suggest about parents' adjustment. The study findings were consistent with previous literature but add new insights, particularly drawing attention to the difficulties faced by bereaved parents in their later grief, when others might view them as having made 'progress'. These findings have implications, discussed later in this chapter.

5.3.2 Study Limitations

There are limitations to this study regarding the diversity of the sample. All participants identified as white and only one male participant was interviewed. The SLR papers were also limited in terms of diversity, with most papers acknowledging an underrepresentation of fathers, as well as culturally homogenous samples. This study used a peer support charity to recruit participants which limited the recruitment pool, particularly as the majority of parents who access the charity are white British. Furthermore, the self-selecting sampling method may have led to a biased sample as bereaved parents with certain characteristics may have been more likely to volunteer to take part. All participants' children died due to illness or accident and findings may therefore not be generalisable to parents whose children have died in other circumstances such as suicide or homicide.

Another issue related to recruiting from a peer support charity is that participants may have some shared experiences or characteristics. For example, it is perhaps unsurprising that a story emerged regarding the importance and value of

peer support, and it is important to note that this may not be the experience of all bereaved parents. Furthermore, attendance at peer support groups has likely influenced participants' grief trajectories and the stories they told regarding this, and other bereaved parents who have not accessed the charity might have different stories or experiences. Several of the SLR papers used similar sampling strategies and described similar limitations.

Another limitation regarding the research is my outsider researcher status, which as mentioned likely influenced the stories told and not told in the interviews. The participants in this study told stories related to an in-group identity of being a bereaved parent, and it is possible that they would have felt more able to share certain stories with someone who shared this identity with them. That being said, my outsider researcher status as well as my position as a trainee psychologist may have encouraged participants to share stories regarding feeling misunderstood by society and professionals, which have important implications, discussed in the next section.

5.4 Clinical Implications

This study highlights the difficulties faced by bereaved parents, particularly in their later grief, with participants telling stories of others assuming that when they reached 'flat ground' they no longer required support, leading to feelings of isolation. This finding has implications regarding what may be considered 'normal' vs 'pathological' grief, and the fact that all participants described their grief as enduring and never-ending may particularly challenge the diagnostic label of "prolonged grief disorder". Diagnostic criteria for this condition include ongoing yearning or preoccupation for the deceased, intense emotions, and difficulty re-integrating to one's normal routine and social life, with diagnosis possible as early as one-year post-bereavement (American Psychiatric Association, 2022). The participants in this

study described a process of never-ending yearning and emotional pain, and their stories challenged the notion of one ever returning to an “old life”, instead describing a life totally and permanently disrupted by their loss. These findings may therefore challenge the diagnostic criteria for or notion of prolonged grief disorder, and highlight the risk of clinicians misunderstanding and pathologising the experiences of bereaved parents.

Participants' stories of their difficulties in later grief also have important implications regarding the timing of interventions for bereaved parents. Participants described how in early grief they most valued practical support and did not find advice from others helpful. It may therefore be that psychological interventions would be most useful to bereaved parents when they are in the ‘flat terrain’, because a) their emotions may have stabilised and b) this is the time when support from others in their lives has likely reduced. This may link to literature related to trauma work which suggests that an individual must go through a “stabilisation” phase before being able to work on their trauma (Courtois & Ford, 2013; Herman, 2001).

In order for appropriate and timely support to be offered to bereaved parents, services will require a better understanding of parental grief, in particular its never-ending and non-linear nature which may challenge some societal and theoretical assumptions. Training related to this could be delivered to primary care services (e.g. GPs), as these services are most likely to be a point of contact for bereaved parents. It would also be useful for psychologists within adult mental health services to be informed regarding parental bereavement, in order to facilitate team formulation and intervention planning for individuals with a history of losing a child, no matter how long ago this occurred. Without this knowledge, there is a risk of societal misconceptions regarding parental grief being enacted by services (i.e.

assuming that bereaved parents have 'recovered' and no longer need support). Any material shared with professionals should be informed by bereaved parents, either through sharing qualitative research findings or involving bereaved parents more directly in training.

Another key finding in this study was participants' reports of feeling disconnected and isolated from others in their grief, which may suggest that psychological interventions should include consideration of bereaved parents' relational networks. One way to address this could be to offer family-based interventions to bereaved parents, in line with research findings that family functioning can have an important influence on the grief process (Delalibera et al., 2015). Kissane and Hooghe (2022) describe ways that family therapy can support bereaved families such as by identifying and bolstering family resources and helping the family to 'reconfigure' after loss. Furthermore, given the study's finding regarding the construction of 'bereaved parent' as a collective identity associated with relief and understanding, it is important that practitioners support bereaved parents to connect with one another, such as by providing group interventions or by signposting to peer support organisations, both of which are reported to have good outcomes for bereaved individuals (Bartone et al., 2019; Laranjeira et al., 2022). Participants in this study highlighted the value of the peer support organisation they had accessed (the charity used for recruitment), and the results of this study will be disseminated to the charity to evidence and inform the support they provide to bereaved parents. This finding may highlight the limitations of non-bereaved professionals' ability to help bereaved parents, and might suggest that it would be most useful for professionals (such as psychologists) to provide indirect support such as offering supervision, consultation or training to peer support communities or organisations.

This way of working aligns with community psychology approaches where psychologists aim to build the resources of particular communities through work such as consultation, advocacy or facilitating connections (Kloos et al., 2012).

5.5 Suggestions for Future Research

This study was one of few studies to utilise narrative inquiry to explore bereaved parents' experiences of grief over time, and has demonstrated the value of this methodology within bereavement research. Participants gave feedback that they appreciated the opportunity to tell their story in its entirety, particularly important given that narrative inquiry is one of the few qualitative methodologies that allows for the preservation and presentation of individual stories as opposed to only amalgamating participant experiences. This points the way for other bereavement studies utilising narrative methodologies, for example studies considering bereavement over time in other family members such as siblings or grandparents.

Given the small sample size of narrative studies (Wells, 2011), alongside the findings clearly showing the enduring nature of parents' bereavement, this study could meaningfully be built upon through larger scale longitudinal research. This could allow further understanding of the nature of parental bereavement over time and the factors that influence this. Only one paper in the SLR (Wheeler, 2001) recruited a large sample of 176 parents via open-ended questionnaire, and as this research is now two decades old, it may be helpful to conduct further studies which gather data from a broader sample of parents. Furthermore, all participants in the current study identifying as white, and future research into parental grief should aim to recruit more diverse samples, including more culturally diverse participants, particularly bereaved parents from racially minoritised backgrounds, in order to

further understand the cultural dimensions of grief and enable culturally sensitive and effective support for all bereaved parents.

One finding of this study which is not well-documented in previous research is that bereaved parents described new challenges in their later grief. Research could investigate this further, for example by exploring what 'progress' means to bereaved parents. Furthermore, future research could seek to explore what support is currently available for bereaved parents in early vs. later grief, as well as what bereaved parents themselves feel their support needs are in later grief. This could include exploring clinicians' attitudes and understandings of parental bereavement and whether this informs assessment, formulation and intervention planning for bereaved parents, particularly those in later grief. The charity partner for this research supports parents at all stages of their grief, and further research into the effectiveness of support for bereaved parents at later stages of their grief is essential in order to offer meaningful support. A review by Dias et al. (2019) of interventions for bereaved parents highlighted that all papers trialed interventions with parents who were in the first few months or years of their bereavement, and therefore future research could pilot interventions targeted at those who are less recently bereaved.

Finally, the silence surrounding parental bereavement as described by participants in this study has significant implications. Future studies could seek to involve bereaved parents in participatory action research, to co-construct materials that challenge stigma and inform health practitioners and wider society of the hopes and needs of bereaved parents, in order to contribute to challenging this silence.

5.6 Final Reflections

In conclusion, this study has further added to literature that suggests that the death of a parent's child is a particularly devastating form of loss, with results

suggesting that bereaved parents feel totally and permanently changed by their bereavement, conceptualised in this study as a disaster irrevocably damaging a parent's world. This study adds new insights to the evidence base, particularly highlighting that as parents make what might outwardly be viewed as 'progress' with their grief (i.e. returning to a normal routine, and experiencing a reduction in intense emotions), they face a number of new challenges, including coming to terms with the permanence of their loss, feeling disconnected from their child, feeling totally changed or broken but under pressure to put on an 'act', and feeling socially alienated and misunderstood.

These findings might challenge societal expectations regarding the bereavement trajectory as well as diverging from some models and understandings of grief. I personally found that my own expectations were challenged during this research, and I have been left to reflect on my research questions and aims which were related to understanding how bereaved parents "adjust to living life" without their child. This phrasing was suggested by EbEs and replaced my suggestion of using the phrase "re-engage with life". Looking back, I can see that my original wording might suggest that parents return to an 'old life' or 'old self' following a period of disruption, and these are possibly the stories I was expecting to hear. This study has helped me to understand that the idea of returning to an old life is not possible for bereaved parents, as their world is permanently changed. I have tried to capture this through the use of landscape metaphor, and rather than returning to a lush, green landscape, I visualised parents having to find ways to adapt and survive in an environment that remains hostile. I feel immense gratitude to have learnt from participants in this way, and hope that I have done justice to their words.

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Appendix A: SLR Search Planning Form

Search Planning Form

Question: What is known about how bereaved parents experience grief over time?

Identify the main concepts of the question (use as many as you need)

Concept 1 Experiences	Concept 2 Bereaved	Concept 3 Parents	Concept 4 Child	Concept 5 Time
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List alternatives keywords, terms and phrases below

Concept 1	Concept 2	Concept 3	Concept 4	Concept 5
Experience*	Bereav*	Parent*	Child*	Time*
Qualitative*	Death	Caregiver*	Infant*	Trajector*
Interview*	Grief	Mother*	Baby*	Long*
Narrative*	Griev*	Father*	Babies*	Process*
	Died		Daughter*	
	Dies		Son*	
	Loss		Neonat*	
	Lost		Perinat*	
			Stillb*	


Appendix B: 'Big Tent' Quality Criteria (Tracy, 2010, p.840)**Table 1.** Eight "Big-Tent" Criteria for Excellent Qualitative Research


Criteria for quality (end goal)	Various means, practices, and methods through which to achieve
Worthy topic	The topic of the research is <ul style="list-style-type: none"> • Relevant • Timely • Significant • Interesting
Rich rigor	The study uses sufficient, abundant, appropriate, and complex <ul style="list-style-type: none"> • Theoretical constructs • Data and time in the field • Sample(s) • Context(s) • Data collection and analysis processes
Sincerity	The study is characterized by <ul style="list-style-type: none"> • Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) • Transparency about the methods and challenges
Credibility	The research is marked by <ul style="list-style-type: none"> • Thick description, concrete detail, explication of tacit (nontextual) knowledge, and showing rather than telling • Triangulation or crystallization • Multivocality • Member reflections
Resonance	The research influences, affects, or moves particular readers or a variety of audiences through <ul style="list-style-type: none"> • Aesthetic, evocative representation • Naturalistic generalizations • Transferable findings
Significant contribution	The research provides a significant contribution <ul style="list-style-type: none"> • Conceptually/theoretically • Practically • Morally • Methodologically • Heuristically
Ethical	The research considers <ul style="list-style-type: none"> • Procedural ethics (such as human subjects) • Situational and culturally specific ethics • Relational ethics • Exiting ethics (leaving the scene and sharing the research)
Meaningful coherence	The study <ul style="list-style-type: none"> • Achieves what it purports to be about • Uses methods and procedures that fit its stated goals • Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other


Appendix C: Study Advertisement for Social Media




Molly, a psychologist in training at the University of Hertfordshire, is working on a research project with us.

Molly is looking for current or previous  members who would be willing to be interviewed about how they have gradually adjusted to living life without their child, and what has helped them in this process.

This research is a great opportunity for us at  to consider how we can improve the support we offer for everyone who joins us.

For more information about taking part, please contact:


Or contact the researcher directly:


Appendix D: Study Advertisement Leaflet

(Charity Logo)

Research into the experience of bereaved parents

Information for Participants

An invitation to participate in a research project with the University of Hertfordshire,

University of Hertfordshire **UH**

Why have I been sent this leaflet?

You have been invited to consider taking part in this research because you have had contact with [REDACTED].

Before deciding to take part, it is important that you understand why the research is happening and what will be asked of you. This leaflet aims to answer any questions you may have about the research.

You can contact the researcher (Molly) if you have any further questions (contact details on next page).

What is the research about?

The researcher is interested in exploring the process of grief, and in particular, the experiences of parents who have lost children.

All bereaved parents will have a unique experience of grief, however the researcher hopes to explore how parents gradually adjust to living life following the loss of their child, and what may have helped them in this process.

This research will also explore how [REDACTED] may have supported parents with this process, and will help to inform the support [REDACTED] offer bereaved parents in the future.

Who can take part?

Anyone who has had contact with [REDACTED] and sees themselves as having gradually adjusted to living life without their child can volunteer to take part in the study.

What will be expected of me?

Participation will involve meeting with the researcher at a time and location convenient for you to take part in a 1:1 interview. Interviews can also be conducted remotely if preferred or made necessary due to COVID-19.

The interview will be a space to tell your story - we would like to hear about your journey from prior to your bereavement up to the present day.

What are the benefits of taking part?

By taking part, you will have the opportunity to share and reflect upon your experiences, which some people find useful.

The researcher aims to publish the research and the research might help to inform the support provided to other families who have experienced the loss of a child.

This research will also be shared with [REDACTED] in the hopes of aiding their service development.

What are the possible difficulties of taking part?

The interview may understandably be an emotional process and it is important to consider this prior to deciding to take part.

The researcher will support you during and after the interview and the interview process can be paused or stopped at any time. You will be offered a debrief sheet after participating providing information about services and resources that may be of help.

Who will know if I take part?

If you contact the researcher directly, only they will know you have decided to take part and your details will not be shared with [REDACTED] unless you provide consent for this.

The information you share will remain confidential and will only be used for the purpose of this study. Your real name will not be used in the write-up of the study unless you want it to be.

What should I do now?

If you are interested in this study please contact the researcher directly via email: [REDACTED]

Alternatively you can ask [REDACTED] at [REDACTED] to forward your details to the researcher: [REDACTED]

The researcher will send you some further information and then arrange to meet if you agree to take part.

If you do not wish to participate you do not need to do anything. Thank you for your time in reading this leaflet and considering this study.

Meet the research team:



Molly



Lizette

Molly is the lead researcher and will conduct the interviews. Molly is a clinical psychologist in training at University of Hertfordshire.

Email: [REDACTED]

Lizette is the supervisor of this study. She is a clinical psychologist and researcher and works at the University of Hertfordshire

Email: [REDACTED]

Appendix E: Study Information Sheet

[Charity Logo]

University of
Hertfordshire



Welcome to our Study Participant Information Sheet

Project title: Bereaved Parents' Narratives of their Journeys Through Grief

Researcher: Molly Parrish, Trainee Clinical Psychologist, [REDACTED]

Supervisor: Dr Lizette Nolte, [REDACTED]

I (Molly) would like to invite you to participate in a research study about your experiences of grief as a parent who has gradually adjusted to living life following the death of your child.

Before you decide whether you would like to take part, I would like you to understand the purpose of the research and what it would involve for you. Please do talk to other people about the research or please feel free to contact me if there is anything that is unclear or if you have further questions.

What is the research about?

This research is being undertaken as part of a doctoral qualification in Clinical Psychology at the University of Hertfordshire.

The death of a child is a traumatic and life-changing event for a parent, and every bereaved parent will have a unique experience of grief. In this study I am hoping to explore the stories of bereaved parents, particularly focusing on how they describe their grief over time and how they may have adjusted to life after bereavement. The research hopes to provide insight into parents' grief processes in order to inform the help they might be offered.

In addition, [REDACTED] are particularly interested in how they may have supported with parents' grief journeys, in order to inform the support they offer bereaved parents in the future.

Why have I been asked to participate?

You will have heard about the study through [REDACTED] social media platforms, website, emails or word of mouth from facilitators or other members of [REDACTED]. You have been invited to take part as a bereaved parent who has had involvement (past or present) with [REDACTED]

Do I have to take part?

No, it is entirely your decision whether you want to take part or not and there will be no implications if you choose not to and you do not have to take part just because you attend [REDACTED] groups or have been told about the study by someone at [REDACTED]. If you decide to take part I will ask you to complete a consent form.

[Charity Logo]

University of
Hertfordshire



What will happen if I take part?

- Once you have confirmed that you would like to take part, I will contact you by phone or email to arrange a convenient time for you to attend a 1:1 interview.
 - We can meet either at your home or a community location convenient for you. The interview can also be conducted remotely via Zoom if you prefer
 - We will need to ensure that whether face-to-face or remote, we are able to meet privately and uninterrupted for at least an hour and a half
- Should both parents of a child choose to take part, interviews will be completed separately.
- The interview will begin by confirming you have given written and informed consent to participate and gathering some basic demographic information from you.
- We will then have a conversation about your experiences. I will ask you to tell me a bit about your child (you are welcome to bring a photograph of your child if you would like to, but this is completely your choice). We will then talk in more detail about your experience of grief over time from the death of your child up until now.
- After our conversation, there will be a period of time when I will be writing up the study. If you would like to discuss the results or give feedback, we can determine the most convenient way of doing that.

Are there any benefits in taking part?

By taking part, you will have the opportunity to share and reflect upon your experiences, which some people find useful. I aim to publish the research and hope this will help to inform the support provided to families who have experienced the death of a child. This research will also be shared with ██████ in the hopes of aiding their service development.

Are there any risks involved?

Although it will not aim to be upsetting, the interview may understandably be an emotional process and it is important to consider this prior to deciding to take part.

I work as a trainee clinical psychologist and am therefore experienced in supporting people with their mental health. I will be available to support you during and after the interview if required. The interview process can be paused or stopped at any time and you will be offered a debrief sheet providing information about who to contact should you feel you need further support after the interview.

How will data be collected and stored?

The interviews will be audio recorded (or video recorded for online interviews) and then written up (transcribed). Recordings and any personal information about you (such as your name and contact details) will be stored on a password-protected drive which only I will have access to, and will be deleted once the study write-up is complete (approx. one year).

I will also ask your consent for the University of Hertfordshire Parent and Family Wellbeing research stream to store your anonymised interview transcript and (separately) basic demographic data (such as your gender and ethnicity) for possible future analysis/ research. This data will be stored securely on the university drive for up to ten years and will not include your personal details. This will only occur with your consent, and should you decide not to give consent for this it will not affect your ability to take part in the study.

[Charity Logo]

University of
Hertfordshire



Will my participation be confidential?

Your participation and the information collected in this study about you will be kept strictly confidential. Only I will be able to match your details with your interview and data will only be used for the purposes of the study.

The research supervisor and examiners will have access to an anonymised transcript of our discussion, and in the write-up of this study, quotes from the interviews will be used to illustrate points being made. Every effort will be made to ensure that you and your family cannot be identified from this text. You will be given a choice to use a pseudonym or your actual name for these quotes.

The only time I would need to break confidentiality is if something you say makes me feel worried about the safety of you or someone else, in which case I may have to share information with others, however I will let you know about this if this is the case.

What happens if I change my mind?

Your participation is voluntary and you are free to withdraw at any time without giving a reason, including after the interview has happened. If you wish to withdraw from the study please let me know.

What will happen to the results of the research?

The study will be written up as part of my doctoral studies and I intend to submit it for publication in a peer-reviewed journal. A summary will also be disseminated to [REDACTED] Research findings made available in any publications and/or reports will not include information that can be directly identifiable without your consent.

Where can I get more information?

If you have any questions or would like to know more about the study, please do feel free to get in touch with me, or my supervisor:

Lead researcher: Molly Parrish, [REDACTED]
Research Supervisor: Dr Lizette Nolte, [REDACTED]

What happens if there is a problem?

If you have any concerns or complaints about any aspect of the study, please do get in touch with my research supervisor Dr Lizette Nolte, [REDACTED]

You can also write to the University's Secretary and Registrar at the following address:

*Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Hertfordshire
AL10 9AB*

Thank you very much for reading this information and giving consideration to taking part in this study

Appendix F: Interview Schedule

Interview Schedule

Prior to interview:

- Introductions - Introduce self, and brief introduction to research context and aims
- Ensure interview location is private and quiet. Explain interview should take 60-90 minutes.
- Check information sheet has been read and understood, provide an opportunity for participants to ask questions
- Review/ signing of consent forms
- Record basic demographic information: age and ethnicity
- Confirm name of the child that has died, year of birth and year of death
- Tell participant if they are uncomfortable answering any questions, they do not need to answer and can let the researcher know
- Tell the participant they should let the researcher know if they want a break, if they have had enough for that day or do not want to continue
- Turn on recorder and confirm consent for this

Interview

I am going to ask you to tell me the story of your grief following the death of X. You can share as much or as little information with me as you want, and there are no right or wrong ways to do this. At times I may interject with some questions but I will mainly be listening, as I would like you to take the lead on telling your story.

The main focus of the interview will be hearing about your grief process - I'm particularly interested in how your grief may have changed over time, and how you have managed to adjust to living life without your child. Before we start to think about this, I wonder if you can tell me a little bit about X and how he/she died?

Key questions:

1. Can you tell me about your experiences of grief from the death of X until now?
2. Can you tell me about how you have adjusted following the death of X? (In other words, how have you been able to move to a place of not being all consumed by grief?)
3. How have [REDACTED] featured in your journey through grief?

Additional prompts:

- How has your experience of grief changed over time? How have you understood / made sense of these changes?
- What have you noticed about how you were thinking / feeling / acting at the time of the death of X, a while after the death of X and now? How have you understood that / made sense of these changes?
- How would you/ someone close to you describe yourself now compared to before X died / soon after X died?
- Have you felt your 'old self' / parts of 'your old self' returning, or a new self- emerging?
- How does X's presence come into your life now and how is that changing over time?
- How do you imagine things will continue to change? If we were to talk again in a year's time, what do you imagine you might say then?
- How were others (friends, family, professionals) part of this process? How were their words or actions helpful or not helpful?

After Interview

- Check in with how participant is feeling
- Go through debrief sheet and next steps including how to contact researcher

Appendix G: Ethical Approval



HEALTH, SCIENCE, ENGINEERING AND TECHNOLOGY ECDA

ETHICS APPROVAL NOTIFICATION

TO Molly Parrish
CC Dr Lizette Nolte
FROM Dr Rebecca Knight, Health, Science, Engineering & Technology ECDA Vice Chair
DATE 13/07/2022

Protocol number: **LMS/PGR/UH/05012**

Title of study: Bereaved Parents' Narratives of their Journeys Through Grief

Your application for ethics approval has been accepted and approved with the following conditions by the ECDA for your School and includes work undertaken for this study by the named additional workers below:

no additional workers named

General conditions of approval:

Ethics approval has been granted subject to the standard conditions below:

Permissions: Any necessary permissions for the use of premises/location and accessing participants for your study must be obtained in writing prior to any data collection commencing. Failure to obtain adequate permissions may be considered a breach of this protocol.

External communications: Ensure you quote the UH protocol number and the name of the approving Committee on all paperwork, including recruitment advertisements/online requests, for this study.

Invasive procedures: If your research involves invasive procedures you are required to complete and submit an EC7 Protocol Monitoring Form, and copies of your completed consent paperwork to this ECDA once your study is complete.

Submission: Students must include this Approval Notification with their submission.

Validity:

This approval is valid:

From: 13/07/2022

To: 30/06/2022

Appendix H: Consent Form



Consent form

I confirm that I have read and understand the information sheet for the study and have had the opportunity to ask any questions I may have.

- Yes
 No

I understand that participation is voluntary and that I may withdraw from the study at any time without disadvantage or having to give a reason.

- Yes
 No

In giving my consent to participate in this study, I understand that voice and/or video recording will take place and I have been informed of how this recording will be conducted.

- Yes
 No

I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled: how it will be kept secure, who will have access to it, and how it will or may be used.

- Yes
 No

I understand that (anonymised) data collected from the study may be shared with authorised individuals from the University of Hertfordshire and [REDACTED] where relevant. I give my permission for these individuals to have access to these records and to analyse and publish information obtained from my participation in the study.

- Yes
 No

I give consent for the University of Hertfordshire to securely store my anonymised data for up to 10 years for possible re-analysis or further research in the future. (Opting out of this will not affect your ability to participate in the study, and should you change your mind about this at a later date you can let the researcher know).

- Yes
 No

Anonymity

This study will be published as a university thesis, and for this purpose all data must be anonymous, you will therefore be allocated a pseudonym and your real name withheld. However, this study will be shared in other ways and I want to give you the option to use your family's real names as I am aware that as a bereaved parent you may wish to honour your child's name. Please state your preferences below (you have the right to change your mind about this up to the point of completion of the study write-up, and can do so by contacting me).

Should this study be published in a professional journal, I would prefer:

- For my family's real first names to be used
 To be assigned pseudonyms

Should this study be used by [REDACTED] (e.g. on their website, in promotion materials or for funding applications) I would prefer:

- For my family's real first names to be used
 To be assigned pseudonyms



I, the undersigned *[please give your name here, in BLOCK CAPITALS]*

hereby freely agree to take part in the study entitled *"Bereaved Parents' Narratives of their Journeys Through Grief"*

Signature of participant.....Date.....

Signature of (principal) investigator.....Date.....

Name of (principal) investigator

.....

Appendix I: Debrief Sheet

[Charity Logo]



Project title: **Bereaved Parents' Narratives of Their Journeys Through Grief**

Thank you for taking part in this study. Through this research we hope to gain a better understanding of how parents begin to adjust to living life following the death of a child, and what may help them in this process.

If you would like more information about the study or would like to know about the findings once all the data has been collected and analysed please contact me: Molly Parrish, [REDACTED]. Unfortunately, I am unable to provide you with your individual quotes and data.

If taking part in this study raised or left you with anything which felt distressing and you feel you may benefit from further support, please do contact one of the following if it feels comfortable to do so:

- Molly on the above email address
- A facilitator at [REDACTED]
- Samaritans on 116 123

Thank you so much!

Appendix J: Transcription Guide (Poland, 2001, p.641)

Table 30.4 ALTERNATIVE ABBREVIATED INSTRUCTIONS FOR TRANSCRIBERS

It is important for qualitative research that transcripts be verbatim accounts of what transpired in the interview; that is, they should not be edited or otherwise "tidied up" to make them "sound better."

Pauses	Denote short pauses during talking by a series of dots (. . .), the length of which depends on the amount of time elapsed (e.g., two dots for less than half a second, three dots for one second, four dots for one and a half seconds). Denote longer pauses with the word pause in parentheses. Use "(pause)" for two- to three-second breaks and "(long pause)" to indicate pauses of four or more seconds.
Laughing, coughing, etc.	Indicate in parentheses; for example, "(coughs)," "(sigh)," "(sneeze)." Use "(laughing)" to denote one person, "(laughter)" to denote several laughing.
Interruptions	Indicate when someone's speech is broken off midsentence by including a hyphen (-) at the point where the interruption occurs (e.g., "What do you-").
Overlapping speech	Use a hyphen to indicate when one speaker interjects into the speech of another, include the speech of the other with "(overlapping)," then return to where the original speaker was interrupted (if he or she continues). For example: R: He said that was impos- I: (overlapping) Who, Bob? R: No, Larry.
Garbled speech	Flag words that are not clear with square brackets and question mark, if guessing what was said (e.g., "At that, Harry just [doubled? glossed?] over"). Use x's to denote passages that cannot be deciphered at all (number of x's should denote approximate number of words that cannot be deciphered). For example, "Gina went xxxxx xxxxx xxxxx, and then [came? went?] home."
Emphasis	Use caps to denote strong emphasis; for example, "He did WHAT?" (Do not use boldface or underlining because such formatting is often lost when text files are imported into qualitative analysis software programs.)
Held sounds	Repeat the sounds that are held, separated by hyphens. If they are emphasized, capitalize them as well. For example, "No-o-o-o, not exactly" or "I was VER-r-r-y-y happy."
Paraphrasing others	When an interviewee assumes a voice that indicates he or she is parodying what someone else said or is expressing an inner voice in the interviewee's head, use quotation marks and/or indicate with "(mimicking voice)." For example: R: Then you know what he came out with? He said (mimicking voice) "I'll be damned if I'm going to let YOU push ME around." And I thought to myself: "I'll show you!" But then a little voice inside said "Better watch out for Linda." Sure enough, in she came with that "I'm in control now" air of hers.

Appendix K: Extract of Coded Transcript

<p>Interview 2 Anonymised Transcript – “Jane” (75 years old) Conducted on 15th November 2022, 5:00pm, at Jane’s home Interview length = 1hr 15 minutes</p>	<p>Apologetic for getting upset, letting interviewer know she will be ok, aware of interviewer’s thoughts/ reaction</p>
<p>Key – Thematic Structural Interactive Performance Context Meaning Making</p>	
<p>MP: So yeah, like, I say, the main focus of the interview is going to be talking more about your grief process. But obviously it would be, you know, helpful to hear a little bit just about Elizabeth as well the circumstances of her death.</p>	<p>Interviewer attempting to make interviewee feel better</p>
<p>SQ I don't know if you would mind, just telling me a bit about Elizabeth and sort of a bit about how she died as well, to start with. And then we'll talk more about your grief.</p>	<p>Losing only child Starting with this sets up interviewee's position as childless mother Assumption that bereavement worse if lose only child</p>
<p>Jane: Yeah, first of all (coughs) I'll get over this, it's just (crying)</p>	<p>A happy life prior to death Letting researcher know that child enjoyed their life, and had good relationship with parents (assumed understanding of “we”)</p>
<p>MP: No, it's the hardest part as well, talking about [this part]</p>	<p>Way of coping with death to remember a life well lived? Telling story chronologically</p>
<p>Jane: Err, she was our only child (tearful)</p>	
<p>MP: Mmm</p>	
<p>Jane: And uh lived life to the full, uh, in every respect. And uh, we obviously had a very good relationship with her. Uh, so she was at school here locally. Um actually the year we moved into this house she happened to go off to university, so... she wasn't brought up in this house,</p>	<p>Unclear what is important about this, possible sadness re living in a home with few memories of child in?</p>
<p>MP: OK</p>	
<p>Jane: Which is quite important in a way. But she would come home from uni with MULTIPLE friends.</p>	<p>Wanting audience to know her daughter was sociable, outgoing etc, use of emphasis and humour</p>
<p>MP: (small laugh)</p>	
<p>Jane: Um, always. Uh,</p>	
<p>She went to university, loved it. And just threw herself, at life, everywhere, and uh it sounds a bit arrogant when I say she was um, when she died there were HUNDREDS of people, her friends from everywhere,</p>	<p>Continued story of a happy, full life Paints picture of a young person who lived life to the full again, is this a way of processing loss? Continued story of child as sociable Wanting audience to know child had an impact on world/ others Assumption that the more people mourn death = bigger impact you had on world, better person you were Portraying daughter as caring and good friend</p>
<p>MP: Mmm</p>	
<p>Jane: were just devastated, you know... because she was so full of life, and she was everybody's friend, and used to be the one that they sobbed, uh, on her shoulder. Um...</p>	<p>Life sounding idyllic before death, lots of extreme language e.g. “to the full”, “in every respect”, “200%”</p>
<p>SQ she went to university that she loved 200% I would say</p>	<p>Fun, humorous tone to narrative, reflecting YPs portrayed personality</p>
<p>MP: (small laugh)</p>	
<p>Jane: and she got very involved. She uh, got very involved in the whole social aspect. Uh and was always from a teenager actually, um, she was quite involved with um, well I suppose voluntary work, um</p>	<p>Communicating child as a good person – who did not deserve to die? Interviewee later states she is religious, possibly jarring that daughter lived a good life helping others and still died</p>
<p>MP: Mmm-hmm</p>	
<p>Jane: I used to do quite a lot, well I still do, I'd drag her along at times where I think it rubbed off a bit, what I was doing (laughing), anyway. She um. She got involved with handicapped groups at university, did voluntary work and ran things,</p>	<p>Communicating self as good parent/ role model, likening child to self Story of child as charitable and good</p>
<p>MP: [OK]</p>	<p>I am making more noises of encouragement than other interviews – possible perception of client as fragile due to age/ tearfulness at start</p>

Appendix L: Extracts of Reflective Journal

'Alison' - Post-interview reflections
 14/11/22 Interview via Zoom

- Not always conversation I was expecting
 - ~ still struggling
 - ~ is getting to place of 'adjustment' unrealistic? Is this as good as can get for some?
- Felt quite raw / honest, not feeling compelled to tell stories of 'recovery'
 - ~ challenging my / societal assumptions?
- I felt quite sad / low
 - ~ picking up on slight hopelessness of narrative?
 - ~ wanting A- to feel better but not wanting to pity her
- Interview 2hrs
 - ~ so much to say
 - ~ felt strange ending, knowing won't speak again ~ this might have made it easier for A- to share though?
- Would have been harder F2F
- warmed to her, liked her

- Felt myself slipping into therapist role at times
 - ~ wanting to ask Socratic qs
 - ~ temptation to formulate, offer advice, challenge beliefs eg: re: guilt
 - ~ here to listen not advise
- Mindful that I'm part of son's cohort
 - ~ Not a parent, student, same age as A's children
 - ~ could relate, could have known him
- Am I wanting linear / neat trajectory?
 - ~ Thesis in back of mind
 - ~ Balancing achieving research aims w/ not influencing P's story.

Reflections throughout coding 7/13/23 - 9/15/23

Alison

- Story grows in detail → death
 - kind recall of day of death
 - PTSD-type memories?
- Sociable, outgoing YP, remembered by others
- Wanting to feel better, wanting someone to help
 - ~ hard when support fades
 - ~ fear of others forgetting
- Totally changed life / self
- Theme of injustice, unfairness
- Tainted view of world, feelings of resentment / bitterness.
 - Life never the same or as good again
- Other people holding hope,
 - reported dialogue from others
- Theme of guilt
 - working through this but still present
 - Role as mother