<u>**Volume One:**</u>

Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.

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Acknowledgement

"Alone we can do so little; together we can do so much."

(Helen Keller)

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Abstract

Background: The death of a child can be a devastating experience for many parents; research suggests it results in an intense and enduring grief which can negatively impact on parents' psychological well-being. Parents with surviving children face the task of navigating their own grief and continuing to parent. Surviving children's responses to the loss of a sibling is complex and sometimes problematic; it is suggested that family functioning is a key aspect of the sibling's response. Psychological literature shows that sibling bereavement has been under-researched (Woodrow, 2007) with little attention given to the quality of the emotional relationship between parent and child, before and after sibling loss.

Aims: Research to explore the stories of bereaved parents and how they experienced their emotional relationship with their surviving children after the death of another child can build on and expand existing literature; resulting in suggestions for clinical psychologist on how to better support surviving relationships at this difficult time.

Methodology: Qualitative methods allow for richness, context and allow parents to tell stories of their emotional relationships with surviving children. Stories are the way in which we give order and meaning to the events in our lives (Gilbert, 2010). Consequently, a narrative analysis was viewed as the most epistemologically and ethically appropriate research method; and most appropriate to answer the research question.

Analysis and Findings: Parents told stories of connection and disconnection in their emotional relationship with their surviving children after the death of another child in the family. Emotional connection and disconnection is influenced by the competing and potentially incompatible tasks of 'parenting' and 'grieving'. Stories of connection with surviving children were constructed as 'putting my living children first' and 'avoiding the fog' of grief; these stories illustrated less connection to the deceased child and parental grief. Conversely, stories of disconnection with surviving children were constructed as getting 'stuck in the fog' of grief and 'remembering'; these stories illustrated more connection to the deceased child and parental grief.

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Chapter 1. Introduction

A dilemma facing any story teller is to decide where the story begins. As a researcher I am faced with the same quandary, how do I begin to tell the reader the story of my research? I have chosen to start by telling the reader about the lens from which I view the world and what I think can be known of it.

1.1 My theoretical position

> *"Epistemology is always and inevitably personal. The point of*
> *the probe is always in the heart of the explorer."*

> *Bateson, 1979, p.93.*

I am a White British woman who was born in London, England in 1970. As I write, I am studying for my Doctorate in Clinical Psychology. As a child taught in a Western society during this era, my early education was greatly influenced by the dominant modernist paradigm. From this world view, questions about the nature of reality (ontology) and what can be known of it (epistemology) are filtered through the lens of scientific enquiry (Guba & Lincoln, 1994). Science is viewed as a logical process which uncovers the truth of an objective reality; the observer is seen as independent from that which it observes (Raskin, 2002).

As I grew, so did the academic debates about science and knowledge. A philosophy that grew in opposition to the modernist paradigm, also known as positivism, was social constructionism which argues that "our understanding of the social world is historically and culturally specific" (Houston, 2001, p.846).   I have come to be influenced by these ideas. Social constructionism views knowledge as a "communal construction" and "objectivity as a relational achievement" (Gergen, 2001, p.803); it assumes that the world is experienced "through culturally shared concepts…[and] language shapes our experience of reality" (Harper, 2011, p.91).

Social constructionism has been described as a group of ""diverse theorists" (Houston, 2001, p.846), underpinned by a scepticism about the "taken-for-granted world" (Gergen, 1985, p.1985) and commonly seen as a relativist position as it

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questions the relationships between the narrative and reality. I feel Bateson[1], a post-modernist thinker although not a social constructionist, captured this idea when he said "the map is not the territory", revealing how we all create representations of the world but these representations are not the "thing" itself (Bateson, 1972, p.57).

The relational construction of knowledge and a belief in multiple truths has influenced my outlook and this study's methodological approach. I have also been influenced by the idea of context (Burnham, 1993) being critical in our understanding of our selves and others. In particular, Bateson's idea that the action of isolating or defining a "thing" limits our ability to understand it – "without context, words and actions have no meaning at all" (Bateson, 1979, p.15).

Another school of thinking that opposed the modernist paradigm was the post-modern critical theorists (including Marx, Gramsci and Foucault). Critical theorists view positivism as "a flawed political theory that reproduces the status quo by encouraging conformity with alleged social and economic laws" (Agger, 1991, p119). Critical theorists suggest that by deconstructing modernist science the unseen value bases are exposed. They suggest that "science no more than fiction can attain absolute truth, no matter how reflexive it is about its own values, assumptions, and methodological choices" (Agger, 1991, p.115).

Relativist epistemological ideas alongside critical theory's determination to uncover positions of power have influenced my thinking and approach to this study. However, I have taken a more pragmatic approach to my ontological positions. I could spend hours thinking and debating the philosophical issues of reality, some of the greatest minds have done so for hundreds of years; however, the world would still be full of social injustice and inequality. This position has been guided by Potter[2] who said:

> *"I am certainly not trying to answer ontological questions about what sort of things exist. The focus is upon the way people construct descriptions as factual, and how others undermine those constructions. This does not require an answer to the philosophical question of what factuality is".*
>
> *(Potter, 1996, p.6)*

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[1] Bateson acknowledges this ideas was derived from Korzybski (1941)

[2] Jonathan Potter is Professor of Discourse Analysis at Loughborough University

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I hope the reader has come to appreciate why I elected to start this story outlining my theoretical position; I believe being transparent about my position and personal context is essential to enable the reader to adequately navigate through the research.

1.2 My personal position

> *"If ever there is tomorrow when we're not together…there is something you must always remember, you are braver than you believe, stronger than you seem, and smarter than you think….."*

> *Christopher Robin to Winnie the Pooh (AA Milne)*

This study developed through my academic life as a doctoral student but the story began much earlier in my personal life. I am the first born child to my parents. When I was born, my parents were a young working class couple from London starting their married life together. A few years into my early life, my sister arrived. We spent a few happy years together as a family. When I was four years old, my sister became quickly and fatally unwell. She died.

This event has shaped my life, and left my parents with the task of learning to live with a devastating loss. As a child I was confused. It left me with the physical loss of my sister and the emotional loss of my parents, particularly my mother.

I am now a mother myself and do not know how and if I could cope with the loss of my child. This study is borne of the tension between both of those positions – how do bereaved parents live with the loss of a child and how does that loss influence their ability to parent their surviving children.

I was curious about how other families navigated this terrain and hoped it would help other families and children along the way.

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1.3 Representing the personal and the theoretical through language.

This study represents the personal and theoretical. Although I have my own experience of death, I do not write from a position of bereavement 'expert', as I feel it is "not possible to become an expert on the death or dying of others" (Fredman, 1997, p.xix). To help me and the reader navigate through the differing positions of personal and theoretical within the study, I have chosen to write in both the third person – the language of academic writing - and the first person – the language of the personal.

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Chapter 2. Setting the Context: Literature Review and Research Aims

2.1 Overview

A systematic and staged literature search was completed over eighteen months to ensure a comprehensive review. See Appendix 1 for more detail.

"Death always has been and always will be with us. It is an integral part of human existence" (Kubler-Ross, 1975, p.1). Consequently, the literature on death and bereavement is vast. This review has aimed its focus on the area of parental and sibling bereavement. Accordingly, the ideas of some of the most influential writers in this area, for example Freud (1917/1957); Worden (1982) and Kubler-Ross (1975) are not an area of emphasis.

The aim of this chapter is to provide the reader with an understanding of the research, theory and debates in parental and sibling bereavement, and provide the context and focus of this study. The first section of this chapter will review the research literature relating to parental bereavement and theories of bereavement. This is followed by a review of literature relating to the death of a child in the family from the perspective of a sibling and its influence on parent-child relationships. The chapter closes by exploring the clinical relevance and aims of the study.

2.2 Losing a child – parental bereavement

> "*To understand your parents' love you must raise children yourself*".
>
> *Anonymous, Chinese Proverb*

We enter the world as infants, dependent on the care and protection of care-givers for survival. If we are lucky, they will comfort and protect us, until we learn to do so for ourselves. In adulthood, becoming a parent can be a life changing experience which can provide a richer sense of self and connection to family and community (Talbot, 2002), even if it carries many demands (Nomaguchi & Milkie, 2003). The parent-child relationship is said to be like no other, as a child is not only an object of love to a parent but also a physical representation of self (Littlefield & Rushton,

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1986). The intense bond between a child and parent is a product of "biological, evolutionary and psychological forces" (Rubin & Malkinson, 2001, p.221). Consequently, the death of a child within a family can be an incomprehensible and tragic life changing event, with the pain and distress parents can feel described as "incapacitating" (Schwab, 1997, p.259).

Before the year 2000, parental bereavement was modestly researched but in recent years there has been a dramatic surge of interest by researchers (Cacciatore, Lacasse, & Lietz, 2014). The next section aims to describe the experience of parental bereavement by reviewing the key research findings and clinical studies in the areas, although it does not attempt to provide a comprehensive account.

2.2.1 Length and intensity of parental bereavement

Sander's (1979) empirical study indicated that the death of a child produces a more intense and devastating grief than that of a spouse or parent. Middleton, Raphael, Burnett and Martinek (1998) criticized early studies for lacking equivalence in bereavement groups and being cross-sectional in design; and they completed their own longitudinal study reporting similar results as bereaved parents demonstrated more intense grief reactions. More recent research also supports this finding (Fletcher, 2002; Hendrickson, 2009)

One explanation of this grief reaction can be found in Wheeler's (2001) qualitative study which suggests the death of a child goes against parents' expectation of the natural order of life and produces a lifelong crisis of meaning. Others have proposed that the inability to protect one's child creates parental feelings of guilt which intensify the grief reaction (Osterweis, Salomon, & Green, 1984; Rando,1984; de Tychey & Dollander, 2008). Talbot's qualitative study describes how mothers experience the death of a child as a "loss of an important part of themselves" (2002, p16). Schiff (1979, p.23) articulated some of this experience when she wrote "when children die, not only are we mourning them, we are also mourning that bit of own mortality that they carried".

Empirical research studies differ in their findings on 'duration' of parental grief with some reporting a period of up to 9 years (McClowry et al., 1987; Laakso & Paunonen-Ilmonen, 2002; Hendrickson, 2009) and others proposing that mourning continues throughout a parent's lifetime (Woolley, 1997; Arnold, Gemma & Cushman,

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2005; Hendrickson, 2009). Lang, Gottlieb, and Amsel (1996) suggest that these differences are due to studies comparing different periods of loss and being cross-sectional in design. Schwab's clinical experience with bereaved parents suggests that the "pain of loss is likely to remain for the rest of their life, although eventually most learn to live with their pain" (Schwab, 1997, p.259). However, Tonkin's clinical work suggests that grief doesn't decline, life grows and gets bigger around it (Tonkin, 1996).

2.2.2 Psychological impact of parental bereavement

Early research studies suggested that despair is a particular psychological feature of bereaved parents (Sanders, 1979). Intense distress, sadness and depression are commonly reported reactions to the death of a child, although the level of distress reduces over time (Wing, Clance, Burge-Gallaway, & Armistead, 2001); parents who experience more complicated grief reactions may not support this finding (see section 2.2.4). More recent research has found that compared to non-bereaved parents, bereaved parents attest to more symptoms of depression and poorer well-being, although later in life most do not live with clinical levels of symptoms or significant disturbance (Rogers et al., 2008). Other research studies have found the highest level of depressive symptoms are experienced shortly after the loss (Lehman, Wortman, & Williams, 1987; Barrera et al., 2007) while others show symptoms are present seven to nine years later (Kreicbergs, Valdimarsdottir, Onelov, Henter, & Steineck, 2004; Barrera et al., 2007).

The qualitative findings from Arnold and Gemma's (2008, p.664) mixed method study reported that 75% of participants described their grief as a "hollow or empty pain inside" which is associated with feelings of loneliness, despair and an "emptiness that can never be filled or recovered".

In line with these results, a Danish case-control study noted an increase in suicidal ideation in bereaved parents which was at its highest during the first month post death of the child with risk declining over time (Qin & Mortenson, 2003). The toll of coping with the loss of a child is demonstrated by research that suggests a quarter of the study's participants reported an increase in their use of drink and drugs (Cacciatore et al., 2014).

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Research evidence demonstrates the psychological challenges of coping with the death of a child; however there is a growing body of research which is offering an alternative outcome of "posttraumatic growth" (Hogan & Schmidt, 2002; Polatinsky & Esprey, 2000; Engelkemeyer & Marwit, 2008). Calhoun and Tedeschi (2001) suggest that growth following bereavement can be found in relationships with others, spirituality and in an individual's sense of self. The parents who participated in Wheeler's qualitative study bring the idea of positive change to life; one parent described how their child had "taught us how to live and die…..[and] I have learned that I have more strength than I knew" (2001, p.59) while another described "if he could have, he would have said, 'walk in the world for me, Mom'" (2001, p.61).

2.2.3 Impact of parental bereavement on physical health

Some researchers have suggested that the death of a child increases mortality rates for parents (Levav et al., 2000; Qin & Mortenson, 2003) while others report no such association (Birenbaum, Stewart, & Phillips, 1996 and Kvikstad & Vatten, 1996). Stroebe, Schutand Stroebe's (2007) review of bereavement health outcomes indicated some evidence to suggest higher mortality rates in parental bereavement, although the studies reviewed were predominately of spousal loss. However, Hendrickson (2009) completed a review of the parental bereavement literature and concluded there are only a few studies and little evidence to confirm an association. Stroebe et al.'s (2007) review also indicated that the bereaved have an increased likelihood of physical health problems. However, Hendrickson's review (2009) concluded there was conflicting evidence on physical health implications and consequently proposes a requirement for more "methodologically sound" studies to fully determine the link between parental bereavement, mortality and morbidity.

2.2.4 Complicated grief and parental bereavement

In recent years, academics have been debating the concept of complicated grief, particularly in regards to its inclusion as a mental health diagnosis within the recently updated Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013). Some academics argue that people who develop "chronic" symptoms of grief (approximately 10%) need to be acknowledged and treatment given (Lichtenthal, Cruess, & Prigerson, 2004; Shear et al., 2011); however, others argue this is an unnecessary complication, with "chronic" symptoms

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such as anxiety and depression being adequately captured in the existing diagnostic system (Bonanno & Kaltman, 2001). Critical theorists suggest the attempt to provide order to the "chaotic" experience of "complicated grief" is a method of medicalizing grief reactions as "abnormal" when they do not fit into society's discourse of loss (Walter, 1996, p.74).

When published in 2013, the DSM-V removed the bereavement exclusion in the diagnosis of Major Depressive Disorder (MDD), allowing for the diagnosis of MDD in the context of bereavement; however, it was proposed that Persistent Complex Bereavement Disorder (PCBD) was considered as a diagnosis warranting further research (American Psychiatric Association, 2013). PCBD is defined by symptoms such as 'persistent yearning', 'preoccupation' and intense suffering occurring a year or more after death. However, these symptoms of "complicated" grief appear to be more severe in relation to parental bereavement, indicated by a recent cross-sectional study which reported bereaved parents displayed higher rates of yearning and preoccupation, anger and caregiver self-blame than other bereaved groups (Zetumer et al., 2015). Almost 80% of parents who lost younger children reported suicidal ideation at some point since their child's death compared with 53% of those who lost other relatives (Zetumer et al., 2015).

2.2.5 Gender differences in parental bereavement

Early research proposes that mothers report a more intense grief reaction than fathers (Rando, 1983). Riches and Dawson (2000) suggest caution in gender 'generalisations' as variation is found in research; however they go on to suggest that fathers are more likely to focus on supporting partners, controlling emotions and managing practicalities, whereas mothers are more likely to feel they have lost 'part of themselves' experiencing feelings of despair, irritability, guilt and less control over emotions. Wing et al.'s (2001) review of gender differences also indicated mothers generally experienced a greater intensity and longer grief reaction than fathers; however, they also noted fathers generally displayed higher levels of denial. Littlewood, Cramer, Hoekstra and Humphrey (1991) suggest this type of response could be unhelpful to fathers as it may reduce their ability to manage grief. This may be influenced by a lack of socially acceptable outlets for men to express emotion (Bryant, 1989). These findings need to be understood in the context of the dominant gender societal discourses which validate expressions of grief.

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A more descriptive account has been presented by Alam, Barrera, D'Agostino, Nicholas and Schneiderman (2012) in their qualitative study of parents whose children died of cancer. Their study reports differences between mothers and fathers, with fathers being more work-focused and levels of grief reportedly being higher for mothers, alongside other gender differences in relation to coping and on-going relationships (Alam et al., 2012).

2.2.6 Parental bereavement and culture

At this point it is important to provide context of the reviewed literature for the reader. As early as 1976, Rosenblatt's (as cited in Stroebe et al., 2001) study reported that across 78 world cultures people had difficulty dealing with the experience of death; however he noted variations in the experience and expression of grief. Rosenblatt (2001) suggests this variation is influenced by societal norms and sometimes political forces. One such qualitative study looks at the discourses of parents who are bereaved in war-torn Israel and identifies an emerging role of anger and social activism in the bereavement process (Lebel & Ronel, 2009). However, there has been comparatively fewer bereavement studies completed in non-Western societies and very few directly relating to parental bereavement (Ho & Brotherson, 2007). Consequently, the research outlined above should be viewed as predominately reflecting the experience of fathers and mothers living in politically stable Western cultures over the last century (Wing et al., 2001).

2.2.7 Summary

In summary, research indicates that on the whole parental bereavement is more intense than other forms of bereavement, and can be long in duration. The evidence is conflicting as to whether parental bereavement is associated with increased rates of mortality and morbidity. However, research suggests a negative impact on psychological well-being, particularly in the initial period after the death of the child; although some parents later come to report personal growth. There is some evidence for gender differences in parental bereavement, but all findings should be understood in light of its historical and cultural contexts.

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2.3 Theoretical models of parental bereavement

The previous section explored the consequences of parental bereavement, this section aims to consider the process of grieving. How do parents who experience the death of a child come to terms with their loss? It has been proposed that some of the theoretical models of bereavement do not adequately reflect the experience of parental grief (Davies, 2004). This section aims to summarise the development of bereavement theory in the United Kingdom and United States of America across the last century using a framework of traditional and new perspectives of grief.

2.3.1 Traditional perspectives of bereavement

Freud was the first to offer a concept of "grief work" proposing that grief is resolved by the "survivor" detaching from the deceased; however, Freud himself found this challenging after the loss of his own daughter writing, "we shall remain inconsolable and will never find a substitute…..[it is a] love which we do not want to relinquish" (Freud, 1917/1957, p.239). Even so, Freud's concepts were developed by Bowlby (1961) utilising his theory of attachment and Parkes' (1972) research with widows, and grief continuing to be conceptualised as a process leading to detachment from the deceased.

Kubler-Ross (1975) developed a stage model, but the model was developed initially based on her work with the dying rather than bereaved, although she did extend this work to include the family. Her large body of work has attempted to humanize death and endeavours to give permission for grief to be shared and "worked through".

Worden (1982) went on to propose a task-focused model of grief which outlines four tasks of mourning. Worden's work has been highly influential for both therapists and academics and is still used today (Hedtke & Winslade, 2004). He suggests the first task of mourning is to gain acceptance of the reality of the death, followed by the second task of learning to live with the pain; third is the task of adjusting to a world without the person who has been lost and the final task is abandonment of the emotional investment in the deceased and a re-investment in on-going relationships.

These traditional approaches to grief – emphasising the process of disengagement from the deceased and working through grief - became the dominant models over the last century; however, Davies (2004) suggests that from the 1980's critics began to

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highlight the limitations of these models, particularly in relation to parental bereavement.

Critics suggested that these models of grief were a "twentieth century phenomena" reflecting the modernist, Western perspective on the "autonomous" individual, leaving little room for the idea of "interdependence" (Silverman & Klass, 1996, p.5) whilst also representing "a positivistic model of science that has stressed how separate people are from each other" (Davies, 2004, p.511).

Wortman and Silver's (1989) review of the bereavement research challenged the assumptions and evidence base of traditional models, and called for an acknowledgement of variability in the bereavement process. For example, Worden's tasks can be critiqued for being presented as "universally relevant across a range of cultural and social dimensions" (Hedtke & Winslade, 2004, p.28). In relation to parental bereavement, Rando (1986) also critiqued these traditional approaches suggesting that as children are a physical representation of the parent, they are 'irreplaceable' unlike other relationships, like a spouse. Rando (1991) went on to suggest that traditional models of grief can 'pathologize' the 'normal' experience of parental grief. Therefore, there was a need for a new approach to theories of parental bereavement.

2.3.2 Newer perspectives of bereavement

New grief theories discarded the idea of ending the emotional connection to the deceased and began to view it as central to the process. Silverman and Klass (1996) posit that this shift in perspective is represented in a shift from quantitative to qualitative research methods; with researchers wanting to understand the complexity of the bereavement experience. One major approach to emerge from this shift is the model of continuing bonds.

Continuing Bonds:

The basic tenet of continuing bonds is the relationship between adjusting to the reality of the death of a loved one whilst also continuing to maintain a connection (Davies, 2004). Klass demonstrated in his decade long ethnographic study how parents maintained bonds with their dead children giving them "solace in the face of irreparable loss" (1993, p.365). This finding was supported by other qualitative

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studies (Rosenblatt, 2000). Talbot (2002) noted in her phenomenological study that bereaved mothers found it 'healing' to remember and maintain a connection with their dead children. Riches & Dawson (1996) found similar results but also suggested that bereaved parents negotiate their bereavement in a social world which often feels isolating.

However, there is some argument as to whether continuing a bond to the deceased is an essential, or alternatively more complicated part of the bereavement process; Stroebe & Schut (2005) reviewed the continuing bonds literature and propose that more research is required to determine who may benefit from continuing bonds with a loved one, and who may find it unhelpful. Field, Gal-Oz and Bonanno's (2003) empirical study found that those who reported more expressions of continuing bonds at five years after the death of a loved one, also reported higher levels of distress and grief symptoms.

Alternative models:

As research began to highlight the differences in bereavement experiences and outcomes, researchers began to look at the characteristics of 'adaptive coping'; a comprehensive review of this body of literature can be found in Stroebe and Schut (2001) and Stroebe and Schut (2010) . One of the main models to come from this area is the Dual Process Model (DPM) (Stroebe & Schut, 1999). See Figure 1.
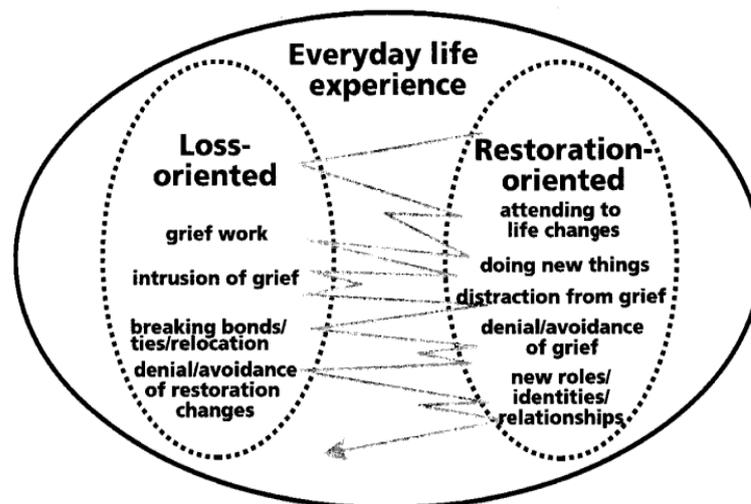
Figure One: The Dual Process Model (Stroebe & Schut, 1999)

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The DPM attempts to incorporate the research ideas in this area and suggests the bereaved have to work through emotions and adapt to an altered reality. The model posits that bereaved individuals 'oscillate' between loss orientation coping which is related to grief work, and restoration orientation coping which is concerned with rebuilding; 'adaptive coping' requires an oscillation between both styles of coping while at other times avoiding them (Stroebe & Schut, 1999). "Oscillation between positive and negative affect/(re)appraisal is understood to be an integral part of the coping process, and to be a component of both loss and restoration-oriented coping" (Stroebe & Schut, 2010, p.279). Parental bereavement research suggests that fathers employ more restoration-orientated coping and mothers use more loss orientation coping (Alam et al., 2012). See Stroebe and Schut (2010) for recent developments in the DPM model.

Finally, another area to be considered is the role of 'meaning-making' after life changing events, such as bereavement (Stroebe & Schut, 2001). Neimeyer's (1999, p.66) critical constructivist approach proposes that "the intimate details of people's stories of loss suggest a complex process of adaptation to a changed reality, a process that is at the same time immensely personal, intricately relational, and inevitably cultural". From this perspective the expression of loss is personal and centrally related to a process of meaning making. Finding meaning following the death of a child, and restoring a sense of purpose has been demonstrated both quantitatively and qualitatively to be associated with better outcomes for parents (see Wheeler, 2001 and Lichtenthal, Currie, & Neimeyer, 2010 for a more detailed account).

As this section draws to a close, it is interesting how this evolution in bereavement research can be associated with a shift in English and American culture towards a more post-modern position; demonstrated by a more critical view of science, a rise in secularism and a world with more knowledge and experience of other cultures and religions (Walter, 1996).

2.3.3 Summary

The traditional models of grief which emphasise the process of 'working through' grief towards detachment from the deceased have been challenged over the last few decades. Theory has moved towards a more individual and textured explanation of

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bereavement with attention given to continued relationships with the dead and the role of meaning making; these theoretical developments appear to more adequately reflect aspects of parental bereavement.

2.4 The death of a child in a family

The focus of this review so far, has been the parental experience of bereavement. Many parents who live through the experience of a child's death have surviving children. The next section will explore how surviving children in the family experience the death of their sibling; specifically sibling bereavement in childhood, as this is a time when young people are dependent on their care-givers. However, as this study collected stories of emotional relationships told by parents and not children, this review will be more limited in its scope.

2.4.1 Children's experience of losing a sibling

Until recent decades the experience of sibling bereavement had been relatively unobserved (Davies, 2003). Cain, Fast and Erickson (1964) presented one of the first research studies on children's responses to the death of a sibling and outlined an array of "disturbed" reactions. Although drawing from a small sample of siblings who were already psychiatric patients (Rosen & Cohen, 1981), this early study recognised that a child's reaction to a sibling death was a result of a complex set of variables.

Pettle Michael and Lansdown's (1986) mixed methods study reported emotional and behavioural problems for a high percentage of children although some did not display any difficulties; nevertheless, across both groups low self-esteem was frequently noted with many negatively evaluating themselves against their ideal or dead sibling. This study is limited by its small sample size, lack of control group and measures taken from the children themselves. However, McCown and Pratt (1985) reported similar findings, alongside Davies (1991) who indicated significantly higher internalising behaviours in bereaved siblings, suggesting they are more likely to turn emotions inwards, becoming low in mood, sad and socially withdraw. A more recent study found that children whose sibling died from cancer 2 to 9 years previously, reported lower self-esteem and personal maturity compared with non-bereaved peers (Eilegård, Steineck, Nyberg, & Kreicbergs, 2013).

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Davies (1999) reviewed the research literature in this area and reports on the most common responses to sibling bereavement in childhood (see Table 1). However, she posits that many of these behaviours are a normal reaction to difficult circumstances; the challenge is the identification of responses that point to a more 'troubled' reaction. Davies (1999) proposes that behaviours which reflect an internalisation of emotion and a reduction in social activity, accompanied by low mood, may indicate a sibling in 'trouble'.

Table 1. Most frequently occurring behaviours in bereaved siblings

Acting out behaviours
• Argues a lot • Shows off • Disobedient
Sadness and Depression
Crying
Loneliness
Anxiety
Guilt
Psychophysiological Behaviours
• Aches and pains • Sleep disturbances • Eating disturbances
Poor school work

Davies, 1999, p. 51

Holliday (2002) completed a review of the sibling bereavement literature for Barnardo's with a focus on research studies using validated measures and control groups and concluded there was little evidence suggestive of a significant rise in psychological difficulties following sibling bereavement. However, the review does suggest problems may arise in particular contexts, including traumatic deaths and family adjustment difficulties. Harrington and Harrison (1999) suggest it is an error to presume children will inevitably present with problematic responses to general bereavement; they point to research that demonstrates personal growth following a death.

The majority of literature in this area is of a quantitative nature, with little qualitative data available (Thompson et al., 2011). One large piece of mixed method research was completed by Fanos (1996) who interviewed children whose sibling died from cystic fibrosis (CF) in childhood. Fanos (1996) reports that adolescents (at time of

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loss), retrospectively reported more depression, anxiety and guilt than the preadolescents or young adults; however she found the younger group to be more emotionally 'defended'. Fanos (1996, p.92) posits that younger siblings avoid 'interpersonal intimacy' for fear of experiencing emotional pain and suggests that this may be related to the siblings' need to hide feelings of anger. The adolescent group were better able to describe their responses which Fanos (1996) summarised as 'global anxiety'.

In summary, research suggests that the childhood response to sibling bereavement is complex and sometimes problematic with a variety of factors influencing its expression.

2.4.2 A framework for understanding sibling bereavement

Pulling together her work in this area, Davies (1999) developed a theoretical model (see Figure 2) of sibling bereavement.
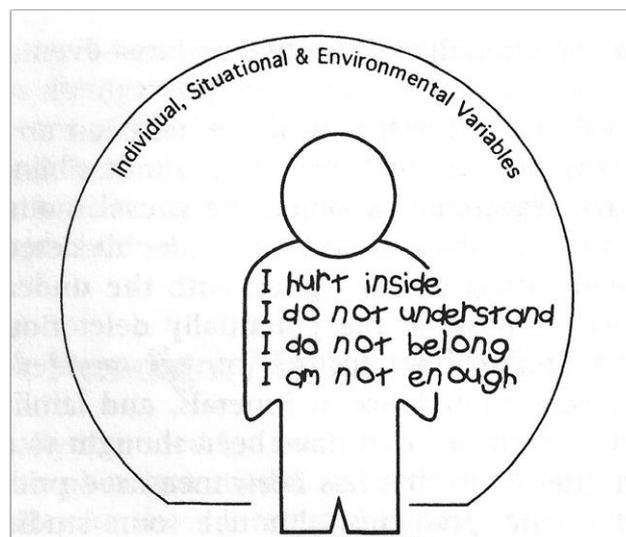
Figure 2. A paradigm model of sibling bereavement (Davies 1999; Davies 2003)

Davies (1999) suggests that children typically respond to a sibling's death by expressing feelings of "I hurt inside" and "I don't understand". "I hurt inside" relates to a child's expression of grief and emotion. "I don't understand" is associated with a child's cognitive ability and understanding of death and grief. Davies (1999) proposes these responses are linked to more individual factors, whereas "I don't belong" and "I'm not enough" are more relational in origin. "I don't belong" is a

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response associated to changes in the family, and siblings sometimes feeling they have 'lost their place'. Davies (1999) posits that the more problematic response of "I'm not enough" is a feeling of inferiority against the dead sibling, connected to individual characteristics and circumstance of the death, but predominately family environmental factors. Davies (1999) model indicates that these responses are mediated by three key variables: individual factors i.e. gender and age; situational factors including cause of sibling death and environmental factors referring to factors about the family. The family will be the focus of the next section.

2.4.3 Surviving relationships – the impact of the death of a child in the family on the surviving relationships between parents and children

> *"Mothers were often completely incapable of providing any love, or even attention to, the remaining siblings, and could barely stumble through the simplest household chores. Our lesser data upon father reactions indicated that for the most part, in accord with our culture role prescriptions for men, the fathers were more overtly calm, stoic and effectively functioning"* *Cain et al., 1964, p. 749*

This clinical observation from 1964 provides an illumination of some parents' bereavement responses from the view-point of the professional observer. It raises the fundamental question of how grieving parents manage parenting duties and maintain on-going relationships with surviving children. Consequently, this section will focus on the family and the interaction between parents and surviving children, after a child dies in the family.

The Family:

The family can been conceptualised as a system or "group of interconnected individuals" (Lamberti & Detmer, 1993, p.56). From this systemic perspective the loss of a child in the family is not an individual experience but one of interconnections and dependence. "The family, operating as a system, both approaches and reacts to loss through a circular process of influence in which all members participate in mutually reinforcing ways" (Walsh & McGoldrick, 1988, p.314). From their clinical

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work, Walsh and McGoldrick (1991) suggest bereaved families have to adapt and create a shared experience and acknowledgement of the death, alongside restructuring and rebuilding anew.

Based on early clinical experience, Krell and Rabkin suggest that as families adjust to loss, surviving siblings can sometimes become unconsciously "positioned" within the family to help "alleviate guilt and control fate" (1979, p.1). These early ideas are supported by the more recent psychoanalytic work of Crehan (2004, p.205) who proposes that "when one's child dies, a counterpart to the self is also lost. Such a death typically produces much unresolved grief" and this can result in surviving children being positioned as:

- 'the replacement child' who personifies the lost child;
- 'the silent sibling' who learns to cope in isolation as expressions of grief are silenced in the families attempts to continue with life as normal;
- 'the scapegoat' is the child who holds and represents the families feelings of anger and hostility; and
- 'the overprotected child' holds the families anxiety and fear over future loss.

Woodrow's (2007, p.209) phenomenological study indicates that death in the family is a "radically relational" experience; however, for siblings it is also an "extremely silent phenomenon" with siblings reporting "to feel like "involved outsiders", part-of but also apart-from the whole grief situation". These ideas lead us to the role of communication in the family.

Family Functioning and Communication:

Parents play a crucial role in helping children manage and cope with bereavement (McCown & Pratt, 1985); and creating an open communication style can help this process (Horsley & Patterson, 2006) while its absence can make it more difficult for children to adjust (Cicirelli, 1995). However, some research studies have not been so definitive and have indicated that communication can have a negative impact, and perhaps effective communication is mediated by timing, content and context (Davies 1999). Supporting this idea, more recent research suggests that not talking, or silence can also play both a role in families adapting and rebuilding a new identity (Baddeley & Singer, 2010).

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A recent study of bereaved parents found that many tried to adopt an open communication style but the authors highlight its complexity when they present a story of a family whose son was driving the car in which their daughter died; the parents felt an open communication style was 'inconceivable' as they did not want to expose their own distress to their son who was already having difficulty coping (Buckle & Fleming, 2010, p.155).

Research also suggests that family functioning is connected to a sibling's sense of self, with lower levels of self-concept associated with less favourable comparisons to dead siblings and not being 'enough' for surviving parents. Farrant (1998) interviewed siblings and also noted feelings of inferiority. One sibling said "I had developed this deep-centred sense of inferiority and I felt a need to prove to my parents that I could be as good as this other child might have been" (Farrant, 1998, p.16). Feelings of inferiority can manifest through children over-achieving or becoming particularly attentive to parent's needs, or parental care-giving (Davies, 1999). This concept is illustrated qualitatively by Schwab's (1997) clinical account of a six year old boy who a month after the death of his sibling was himself hit by a car; a passer-by carried him home, but the boy asked to be put down before he got home because he wanted his parents to know he was alright.

Bereaved Parenting:

It is probable that a parent's ability to provide an open communication style with their child will be impacted by their own grief. Cain et al., (1964, p.749) articulated the potential impact of parental grief on the surviving sibling in their early study describing bereaved mothers as "withdrawn, preoccupied and depressed". Horsley and Patterson's (2006) more recent research reports that adolescents often felt their parents' grief was 'so intense' they would attempt to protect their parents from any further upset. However, Pettle Michael and Lansdown's (1986) mixed method study found no relationship between parental grief and sibling adjustment. In contrast, Demi and Gilbert (1987) found a correlation between parental grief and corresponding child grief patterns, but no connection from child to parent. Davies (1999) only cites these two studies and suggests more research is required in this area.

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Buckle and Fleming's (2010) qualitative grounded theory study focuses on the experience of five mothers and five fathers parenting after the death of a child. They describe bereaved parenting as 'living the duality of devastation and regeneration' (Buckle & Fleming, 2010, p. 39) (see Figure 3). The study describes the "dual tasks" of parenting and grieving and suggests that some parents felt surviving children became 'relatively inconsequential' while for others a prime source of motivation (Buckle & Fleming, 2010, p.117). Some experience a sense of being able to parent at a certain level but with a "disconcerting awareness" of caring for their surviving children, "but just barely" (Buckle & Fleming, 2010, p 120); one mother described not being physically separate from her children but offering little emotional support.

The research provides a richness of description about the experience of parenting while grieving the death of a child and the authors note the variability in the parents' abilities to meet their parental 'obligation', but it does not explicitly reveal the emotional and inter-relational aspects of the parent-child relationship.
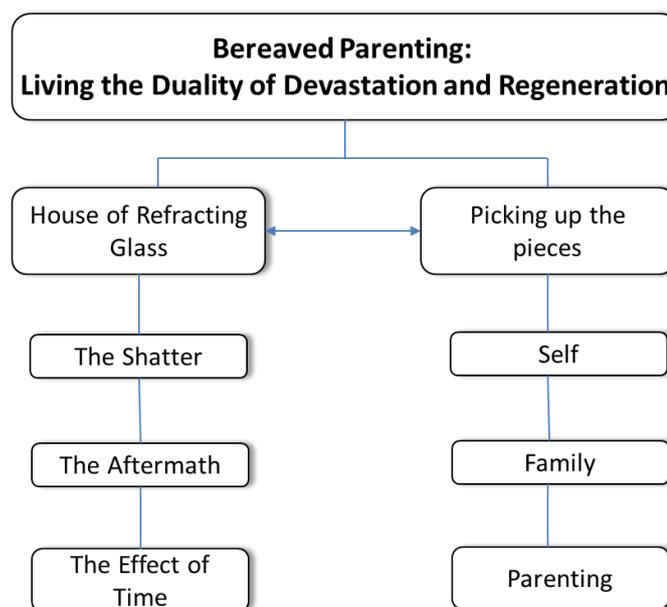
Figure 3: Buckle and Fleming's Hierarchical Category Structure of Bereaved Parenting (2010, p. 37)

The inter-dependency of the parent-child relationship and the quality of that relationship has been described theoretically in bereavement literature (Krell & Rabkin, 1979 & Schwab, 1997) and from a psychoanalytical perspective (Crehan, 2004 & Charles & Charles, 2006); but there is little research which richly describes

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the quality of this central relationship over time, and how it is impacted by the death of a child in the family.

The nature of the parent-child relationship is central to the expression of parental bereavement; it seems logical that this relationship would also be central to the surviving sibling's bereavement and on-going development. However, there is a paucity of research which examines the dynamics of surviving parent-child relationships and their quality over time - before and after the loss of a child in a family. One of the possible explanations is that the Western view-point is biased to explanations of phenomena from an individual position; "there is little place in this model for any idea of individuals as interdependent and living in a web of relationships" (Klass, Silverman, & Nickman, 1996, p.15). Klass et al., (1996) suggest that society holds an idea that people are only capable of managing one relationship at a time, but being part of many relationships contemporaneously is part of the "human condition".

Summary:

Sibling bereavement research is predominately quantitative in nature and suggests that the childhood response to sibling bereavement is complex and sometimes problematic and is mediated by individual, situational and environmental factors. The family is a system of mutual support and influence. Family functioning, in particular open communication, has been shown to influence the surviving child's feelings of self-worth although the context of the family situation needs to be more fully understood. There is little research on the impact of parental grief on sibling adjustment. More problematic sibling bereavement responses appear to show a relationship to the family environment. For a child, the parent-relationship is central to relationships with the family and themselves.

2.5 Summary and aims of study

Research would suggest that the experience of losing a child creates an intense grief that can be long in duration. Parental mourning can have a negative impact on psychological well-being, particularly in the initial period after the death of the child but over time many parents can identify areas of personal growth. Parents who experience the death of a child often have surviving children. They are faced with the

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task of navigating their own grief and continuing to parent. Surviving children's responses to the loss of a sibling is complex and sometimes problematic. Research suggests that bereavement reactions are mediated by individual factors, situational circumstances and environmental factors. Family functioning, in particular open communication has been shown to influence the surviving child's feelings of self-worth, although quantitative accounts are not definitive on the relationship between parental grief and sibling adjustment. However, the relationship with the primary care-giver has to be a central aspect to the child and the family environment. Psychological literature shows that the experiences of bereaved siblings have been under-researched (Woodrow, 2007) with little attention given to the quality of the emotional relationship between parent and child, before and after sibling loss.

Consequently, research to explore the stories of bereaved parents and how they experienced their emotional relationship to their surviving children after the death of another child would build on and expand existing literature. A qualitative study would provide richness, context and give space for parents to tell their stories of their emotional relationships with surviving children.

2.6 Clinical Relevance

Families are altered irrevocably by the death of a child. This personal and potentially devastating experience can have significant implications for relationships in the family. These relationships can provide the support and understanding required to navigate the bereavement process, or can complicate it. This research hopes to gain a richer understanding of the impact of this loss on the parent and child relationship and to help identify ways in which these relationships can be supported to improve bereavement outcomes for all.

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2.7 Research Questions

The main research question is: how do parents story their emotional relationship to their surviving child or children after the death of another?

This will be explored through the following specific research questions:

(i)   What stories do bereaved parents' tell about their emotional relationship with their surviving children over time?

(ii)   What do parents say about the influence on their emotional relationship with their surviving children?

(iii)   What stories do parents imagine their children would tell about their emotional relationship with their parents?

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Chapter 3. Methodology

3.1 Overview

My aim within this chapter is to elucidate to the reader the process of research undertaken to provide a context for their reading of the findings and aid their assessment of the study's credibility. This chapter will begin with a rationale for the use of a qualitative methodology and justification of a narrative inquiry. This will be followed by the ethical considerations of the study. At this point the reader will be provided with details of the research design and the process of data collection and analysis. The last section of this chapter will review issues of quality in qualitative research including reflexivity, credibility and trustworthiness

3.2 Methodology

3.2.1. Moving from epistemology to methodology

My own theoretical position was outlined in the first chapter, and is now revisited in relation to the methodological approach of this study. Put simply, epistemology is a "justification of knowledge" and methodology a "justification for the methods of a research project" (Carter & Little, 2007, p.1317). Methods can be defined as the "procedures, tools and techniques of research" (Schwandt, 2001, p.158).

A researcher's position on the construction of knowledge should strongly influence the methodological approach taken in an investigation (Langdridge, 2004). Carter and Little (2007) suggest that epistemology influences the relationship between the researcher and participant, approach to demonstrating quality of method and the researcher's communication with the audience. My own position has been influenced by relativist epistemological ideas and I endeavour to explain how these have shaped my approach to this investigation.

From a relativist epistemological position, knowledge is constructed relationally and is historically and culturally situated, leading to the idea of a single 'truth' as problematic and promoting a position of multiple perspectives. Therefore "the goal of research is less to generate incontestable 'facts' than to discover and explore the unique and common perspectives of the individuals being studied" (Stroebe et al., 2001, p.105).

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From this approach, the researcher and subject of research are thought of as "conscious beings interpreting and acting on the world around them within networks of cultural meaning" (Madill, Jordan, & Shirley, 2000, p.9).

With this epistemological perspective and research aim of exploring bereaved parents' stories of their emotional relationship with surviving children, the most fitting methodological approach to this inquiry was deemed to be qualitative in nature. Quantitative methods attempt to quantify human experience, whilst qualitative approaches allow for detailed and individual investigation resulting in richness of data and exploration of experience. Qualitative research typically uses the "raw material" of "ordinary language" (Barker, Pistrang, & Elliot, 2011, p.72) to explore meaning and the underlying processes of a phenomena, it does not attempt to predict outcomes (Langdridge, 2004).

A large amount of bereavement research has used quantitative methods; however qualitative methods can "paint a picture of bereavement that is far more complex and less tidy than that suggested by the artificially simplified and controlled canvasses of quantitative questionnaires…..[and are] better positioned to introduce novelty, scope and depth to the study of bereavement" (Stroebe et al., 2001, p.113).

There are differing approaches to qualitative research and the next section aims to articulate why a narrative inquiry was chosen, and how this choice was guided by my epistemological position.

3.2.2. The case for a narrative inquiry

The experience of story-telling can be traced back to early human history. Narrative as a qualitative method of social research, has only gained popularity over the last few decades (Squire, 2008). Its academic roots originate from two coinciding movements, the western post-war humanist approach in psychology and sociology, and the post-structural, postmodern and deconstructionist approaches in the humanities during the 1970's (Squire, Andrews, & Tamboukou, 2013).

What is a narrative?

It is proposed that story-telling helps people make sense of their world and themselves (Bosticco & Thompson, 2005). Narratives have been described as the way individuals "organise their interpretations of reality; the content and structure of

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these interpretations are changeable dependent on context" (Murray & Sargeant, 2012, p.163). Riessman (2008, p.8) posits that narratives are 'tales' which usually depict "a rupture from the expected"; and these 'tales' should be viewed as an interpretive process as they attempt to "mirror the world rather than copy it". The key features of a narrative are the 'tellers' storied account of events over time, which give meaning and explanation of 'why' the 'teller' did what they did (Bruner, 1991).

From a social constructionist perspective, knowledge is not an individual possession but something people jointly create, including the use and construction of language (Gergen, 1985, p.270). These ideas extend to the concept of identity formation, and the role on-going narratives of individuals, families and communities construct identity (McAdams, 2001); "identity is a by-product of multitudes of dialogues with others around us who validate us to be who we are" (Hedtke & Winslade, 2004, p.7). Narrative identities are created and influenced by the wider contexts of culture, history and societal discourses (Baddeley & Singer, 2010).

The choice of narrative inquiry (NI) over other qualitative methods

There are a range of qualitative methods available. A narrative inquiry (NI) was selected for a number of reasons. Firstly, NI fits with my theoretical position as it sits within the field of relativist methods allowing for an exploration of individual stories whilst also considering the context from which the stories have been told, taking account of the influence of family, groups and society. Some qualitative approaches, such as thematic analysis, which sit more firmly in a realist position, were ruled out due to a lack of theoretical fit and my opposition to a categorisation of experience without context (Harper & Thompson, 2011).

Secondly, an assumption of NI is that stories told are "sequential in time and meaningful" (Squire's, 2008, p.17) which is particularly relevant to the exploration of parent-child emotional relationships. Emotions and relationships are not a static phenomenon, but dynamic and changeable over time. Consequently, it was felt interpretative phenomenological analysis (IPA) (Smith & Osborn, 2003) which aims to garner an understanding of an individual's subjective experience of a phenomenon would not capture the temporal and dynamic nature of relationships.

Thirdly, within NI, language is regarded as a 'construction of reality', whereas IPA relies on the validity of language to explore an individual's experience (Willig, 2008).

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IPA relies on participants' abilities to adequately articulate their experience through language; as this study is exploring the potentially traumatising experience of the death of a child, a reliance on complex language did not seem an adequate approach because traumatic experiences are often difficult to articulate (Brewin, Dalgleish, & Joseph, 1996), and NI allows for a broader consideration of context and societal influences on what is spoken, and even unspoken. Even though language is central to a NI, it was viewed that more language focused methods, such as discourse analysis, may not provide sufficient attention to the event of the death of the child. A NI was viewed as a more flexible and varied method allowing for exploration of events, use of language and the 'how' of story-telling (Riessman, 2008); consequently, NI appeared a more fitting method for a explorative study on relationships and bereavement.

Fourthly, the role of society and its influence on the individual, the stories they tell and their sense of identity can be clearly articulated in NI. It has been suggest that a child is important in the mind of a parent but also "an active member of the parent's 'audience', continually involved in maintaining the parent's own identity. A child's death can therefore fundamentally threaten a parent's or sibling's sense of self" (Gordon Riches & Dawson, 2000, p.20). As individuals create and construct favoured stories of their experience, so do families, community groups and societies. NI allows for an exploration of the societal influences that may shape the stories bereaved parents tell and their sense of identity.

To summarise, a parent's relationship with their child is intensely personal and the death of a child can be a traumatic event; the use of a narrative approach to investigate these experiences allows space for parents to tell detailed stories over time, in their own words whilst acknowledging their context. This approach is not attempting to provide common categories of experience but hopes to capture the 'wholeness' of the experience. Consequently, a narrative analysis was viewed as the most epistemologically and ethically appropriate research method; and the most appropriate to answer the research question.

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3.2.3 Narrative methodology

Narrative analysis is not a defined and structured methodological approach which provides the researcher with protocols or clear accounts of data analysis (Squires, 2008). Consequently there are multiple approaches to the analysis of data and these have been classified in different ways (see Riessman 2008; Squire 2008; Wells, 2011). I will now provide the reader with an overview of one way of thinking about the family of narrative approaches.

The most straightforward approach to NI is thematic narrative analysis, a method focused on the content of the narrative with little space given to context (Riessman, 2008). Two other methods which have generated much academic debate are defined by Squire et al., (2013) as event-centred approaches (Labov, 1972) which focus on narratives of single events versus experience-centred approaches (Ricoeur, 1984) which focus on a wider definition of experience narratives; however, both assume that narratives give external expression to "individual, internal representations of events, thoughts and feelings" (Squire et al., 2013, p. 5). Differences emerge in regard to each method's view on the stability of these representations; the event-centred approach assumes stability in individual representations, whereas experience-centred researchers suggest they can change over-time and across context. This aspect of narrative has been broadly termed the 'whats' of a narrative (Smith & Sparkes, 2009).

A third narrative form of inquiry addresses the social or co-construction of stories, where narratives are not a representation of an internal state but a social act developed through dialogue (Squire et al., 2013). Riessman (2008) describes this approach as 'dialogic/performance analysis', with others call it the 'how' of the narrative (Smith & Sparkes, 2009). Riessman suggests it is "a rather broad and varied interpretative approach" allowing for choice and selection of methods (2008, p.105). Researchers using this approach are more inclined to explore how stories are developed through talk; some focus on how social identities are performed and assigned while others are interested in the extent narratives are developed or restrained by social and cultural influences - this area could be viewed as the 'why' of the narrative (Squire et al., 2013).

This study is interested in parents' stories of their relational experiences with their children, the breadth and flexibility of dialogic/performance analysis allows for an

exploration of these stories whilst also accounting for context, identity and societal influence. Additionally, my role as researcher and bereaved sibling can be reflexively considered and accounted for in the co-construction of the stories told by parents and my re-telling to the reader. Consequently, this method will be used as a guiding framework for data analysis. More detail is provided in sections 3.6.2 and 3.6.3.

3.3 Ethical Considerations

Stroebe et al. (2001) suggest that ethical issues within bereavement research had been largely overlooked until 1995. Stroebe et al. (2001) propose that alongside the normal ethical guidelines (British Psychological Society, 2009) a bereavement researcher should consider an additional consultation with the bereavement research community, if possible including participant involvement. Consequently, a key approach of this study was to try to involve others that work in the field and parents who have lived through the death of their child.

A charity based child bereavement service (CBS) was contacted and agreed to support the research and help with the recruitment of participants. The advice and guidance from everyone involved at the CBS has significantly shaped the design of this study.

3.3.1 User involvement

At the CBS many of the experienced members of staff working directly with bereaved families also had their own bereavement stories, and some had experienced the death of their own child. I worked most closely with two senior members of the team, and both had experienced the death of their own child. One of them helped in the development of the procedural design of the research, reviewed all the written communication to families (including the research interview) and helped filter and verbally recruit potential participants. The other reviewed all written communication and participated in a pilot interview. A small example of their input into the study was in use of language, particularly in relation to the word 'loss'; I came to understand that children had not been 'lost' waiting to be found, the children had died.

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3.3.2 Process of ethical approval

Ethical approval of the study was obtained from the CBS staff bereavement team followed by formal approval from the CBS board (see Appendix 2). Final approval was sought from the University of Hertfordshire Ethics Board (see Appendix 3).

3.3.3 Informed consent

Potential participants were contacted by phone by the head of the CBS bereavement service to enable a conversation and answer any questions. Following this conversation, families who indicated an interest in participating were posted a letter of invitation and a detailed information sheet explaining the study's aims (see Appendix 4 & 5). The participant's role is detailed including their rights to confidentiality, anonymity, withdrawal and provision of on-going support from CBS if required. A further opportunity for questions was provided before consent forms were signed.

3.3.4 Confidentiality and anonymity

Great care has been taken to maintain confidentiality and anonymise data and quotes. Interviews were recorded on an audio digital recorder, downloaded and saved onto a password protected computer hard-drive. Original recordings were then deleted. Consent forms and demographic information sheets (see Appendix 6 & 7) were scanned and held digitally. Paper copies were confidentially destroyed. Any computer documents were password protected.

Each participant and family was anonymised and codes given. Any identifying information has been removed and pseudonyms have been used in transcripts. Working paper transcripts were anonymised and stored in a cabinet only accessible to the researcher when not in use. Data will be held for a period of up to five years after the submission in June 2015.

Participants were informed that due to the small sample size anonymity of stories is particularly challenging, but the focus of the research is on the story of the parent-child relationship rather than more identifiable life events which is potentially a protective factor to anonymity.

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3.3.5 Participant well-being

Firstly, any families deemed to be vulnerable were excluded from the potential sample (see inclusions and exclusion criteria in section 3.4.1). During the recruitment process no pressure was placed on families to participate.

Participants could choose to be interviewed at home or at the CBS offices[3]. Participants were informed that a family member or friend could come with them for support to the interview location, but not in the interview room. Before discussing and signing the consent form at the interview, participants were reminded of the potential risks of participating and their right to suspend or end the interview at any time.

The researcher was mindful and sensitive to any potential signs of distress individuals may have felt during the interview. After each interview, participants had the opportunity to feedback and discuss any concerns. Participants were provided with the CBS team's contact details and informed that they could make contact if they needed any additional support.

None of the participants requested additional support. However, one of the participants felt unable to answer one of the research questions - "If your child was here with us now, I am wondering what you imagine they might be saying about their emotional relationship with you" - during the interview. After interview this participant contacted me via email. Initially I was concerned about the participant's well-being and sought advice from my supervisor, however it transpired that she wanted to ask her children the unanswered question, and let me know their responses. .

3.4 Design

3.4.1 Sampling strategy

Sampling refers to the process of identifying and obtaining participants. This study used a purposive sample which refers to a sample selected according to the requirements of the research question (Barker et al., 2011). The number of participants required by a narrative study varies dependent on research aims and level of analysis required (Wells, 2011). Consequently, a purposive sample strategy

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[3] Risk was assessed and the CBS home working policy followed for home visits.

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was used to initially identify approximately five parents of families who had suffered the death of a child whilst having surviving children and had been supported by the CBS. After each interview the length and richness of data collected was considered before another participant was recruited.

Inclusion criteria were:

(i)   the death of the child occurred at least 2 years prior to interview to ensure families were not at their most vulnerable and had been supported by the CBS;

(ii)   the family had surviving children who were no older than sixteen years old at the time of death;

(iii)   parents deemed to have a 'good enough' on-going relationship with the CBS service, to ensure they would feel able to access support post-interview if required.

Exclusion criteria included:

(i)   currently undertaking active therapeutic work with the CBS;

(ii)   parents identified as vulnerable.

3.4.2 Recruitment process

A list of past CBS clients who had experienced the death of a child according to the inclusion criteria was compiled and then screened according to exclusion criteria.

Recruitment was staggered, with only one or two families contacted at a time, over a period of a few weeks. Both parents were invited to participate. As outlined in 3.3.3, families were initially contacted on the phone; if the family were interested they were posted a letter of invitation and a detailed information sheet explaining the study's aims (see Appendix 5 & 6). At the end of the information sheet, different ways of contacting the researcher to confirm agreement to participate were offered (post, email and telephone contact). If no contact was made, families were not followed up as recruitment was on an 'opt-in' principle.

If one or both parents made contact with the researcher, they were contacted individually and asked if they had any questions or concerns about participation; at this point a location and time for the interview was confirmed.

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3.4.3 Participants

Basic demographic information (see Appendix 7), obtained before the research interview and after consent was obtained, and provided to help the reader locate the sample and individuals within their context (Elliott, Fischer, & Rennie, 1999) (see Table 2). Provision of this information by participants was optional, and the request for GP details was to ensure care could be provided if the interview caused any distress.

Although both parents were asked to participate in all the families contacted, only one couple choose to both participate, both were aware of their partner's participation. Consequently, extra care has been taken to anonymise the details of their stories to protect anonymity. Each story has been presented independently with identifying information changed in both stories. Further detail on the approach to the process of analysis   can   be   found   in   section   3.6.

Table 2: Sample Demographics [45]

Pseudo Names	Age (at interview)	Gender	Marital Status (at interview)	Ethnicity	Number of years since death of child	Age and gender of child that died	Number of surviving children	Age and gender of surviving children (at time of death)	Number of children born post child death
June	55	Female	Separated	White British	8 yrs	18, male	2	21, female 10, female	-
Louise	47	Female	Married	White British	4 yrs	17, male	2	15, male 7, female	-
Claire	Not provided	Female	Married	White British	5 yrs	16 months, female	2	8, female 2, male	-
Mary	Not provided	Female	Married	White British	5 yrs	2 years, female	1	11, female	1
Andrew	45	Male	Married	White British	4 yrs	13 months, male	1	9, female	1

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[4] Presented by earliest to latest date of interview

[5] Some specific elements of the demographics have been slightly changed to preserve anonymity (i.e. age of surviving children)

3.5 Procedure and Data Collection

3.5.1 Data collection – the research interview

There are many methods of obtaining data for a narrative analysis; the research interview, the most widely used method, was chosen for this study (Riessman, 2008). There is some debate in the academic literature about the use of research interviews with criticism of data being captured in un-naturalistic settings and researchers not treating the material as an 'interactional' object (Potter & Hepburn, 2005). However, in my view NI is well placed to take account of these concerns.

Interviewing has been described as a "conversation with a purpose" (Banister, Burman, Parker, Taylor, & Tindall, 2006, p.51) which can allow exploration of experiences, thoughts and emotions. This study used a semi-structured interview schedule (see Appendix 8) enabling a focused investigation of the research area but providing flexibility to respond to participants as required (Banister et al., 2006). This is particularly important when the aim of the research interview is to create an atmosphere which provides the possibility of extended story telling (Riessman, 2008).

3.5.2 Development of the interview schedule

Using the research questions as a guide, the interview schedule was developed with the aim of creating a flexible structure which was focused in its intent but enabled "a space for a narrative to be heard" (Wells, 2011, p.30). To do that the following issues were considered in construction of questions:

(i)   Questions which were non-judgemental in their stance and helped to convey empathy for the teller's position (Wells, 2011)

(ii)   Questions which were open-ended, with a single focus and contained non-academic language (Wells, 2011)

(iii)   Follow-up questions, for example "can you remember when…" (Riessman, 2005, p.25) which relate to specific and concrete times and places.

(iv)   Questions that develop a "chronological sequence" for the narrator (Riessman, 2005, p.25)

A draft schedule was developed and then reviewed with my supervisor and a member of the CBS team. At this point, a decision was made not to directly ask the

interviewee about the child who had died, as it was perceived that the dominance of this story may overshadow the production of an alternative narrative about surviving relationships.

Additionally, during the review with the CBS staff member an extra question was added about the interviewee's understanding of the term 'emotional relationship'. As language is a conduit to understanding and this term is central to the research question, it was felt a space for clarification was required. Mishler (1986, p.52) suggests "an adequate understanding of interviews depends on recognising how interviewers formulate questions and how respondents frame answers in terms of reciprocal understanding as meanings emerge during the course of the interview".

When a final draft interview schedule was agreed, a pilot interview was arranged and completed with a CBS team member. After the interview, the schedule was reviewed with the interviewee and supervisor and only minor amendments were made. However, a more significant amendment was the introduction of a question in regard to the death of the child. On reflection it was clear that by not providing space for this story, the narrative collected was stripped of crucial context and meaning.

The final interview schedule can be found in Appendix 8

3.5.3 The process of collecting participants' stories

Participants choose the location of their interviews, with all being completed at the CBS clinic or in participant's home. All participants were interviewed once; duration varied from one to two hours in length. All interviews were recorded digitally on an audio recorder.

At the beginning of the interview participants were given space to ask any questions, were taken through the consent form and demographic information was obtained. If it was felt more time was required to establish an adequate rapport, participants were asked general questions about their home life (see Appendix 8), before the more intimate areas of the interview schedule were explored.

As an interviewer I recognised my role in the co-construction of the narrative and aimed to deliver the interview in an active and conversational style (Wells, 2011). This approach hopefully provided greater equality in the distribution of power within the interview setting (Riessman, 2005). I was also mindful of the importance of "the

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interviewer's emotional attentiveness and engagement and the degree of reciprocity in the conversation" (Riessman, 2005, p.24). I felt this was particularly relevant considering the sensitive material of the research topic, alongside my own position as a 'bereaved sibling' which had been shared with participants in the information leaflet (see Appendix 6); although my status was only referred to briefly once within the pilot interview.

3.6 Analysis of parents' stories

3.6.1 Transcribing the stories

The process of taking auditory speech which is momentary and performed in context, into "a static, permanent and manipulable form" is the act of transcription (Lapadat, 2000, p.204). The choices made by a transcriber can be seen as "both interpretive and political" (Lapadat, 2000, p.204). From a NI perspective, collected stories are co-constructed and transcriptions are inevitably "incomplete, partial and selective".

Being mindful of my role as researcher in the production of transcripts the following choices were made. The complete audio recording was converted to text verbatim. This task was completed by a paid transcriber. The paid transcriber signed a confidentiality agreement (see Appendix 9) and recordings and transcriptions were delivered securely.

I then amended each verbatim transcript using Poland's (2002) transcription system; this is based on Silverman's (1993, cited in Poland, 2002) conversational analysis convention which aims to capture the syntax of verbal conversations and is extensive in scope. However, Poland (2002, p.641) developed an abbreviated version (see Appendix 10) which can reflect conversational features (including pauses, expressive sounds, interruptions and overlapping speech) and was used in the production of final transcripts.

3.6.2 Guiding Framework

It has been suggested that one of the strengths of NI is the variety of strategies that can be used when analysing data as "there are no formulae or recipes for the 'best' way to analyse the stories we elicit and collect" (Coffey & Atkinson, 1996, p.80). Riessman (2008, p.200) invites researchers to 'interrogate' different approaches and

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then "adapt them to your research problem". Using that invitation, this study was framed by the dialogic/performance approach (see section 3.2.3) encompassing the 'what', 'how' and 'why' of narrative. This multi-level approach reflects the position of Smith and Sparkes (2009) who suggest that varying methods and levels of analysis are required to reflect the complexity of the stories collected. As there is a paucity of narrative studies of bereaved siblings or parents, the stages of analysis were guided by other researchers' studies.

3.6.3 Stages of analysis

As already outlined, my first contact with the audio recordings was whilst amending the verbatim transcripts using Poland's (2002) method. After all transcripts were finalised, each narrative was analysed in turn, using the following stages:

Stage One – Getting immersed in the story. During this stage I re-listened to the audio recording whilst reading the final transcript and made any final amends.

Stage Two – Reflexive and reflective reading. Influenced by Brown's narrative study (1998), I read the stories whilst fully attending to my own filter, considering my position, feelings and thoughts which was particularly relevant considering my 'bereaved sibling' context. I also reviewed my reflective notes made after each interview and began a process of capturing on-going reflections during the analysis process. See Appendix 12 for examples.

Stage Three – Reading for structure (the narrative 'what'). The 'what' of narrative looks at the way a story unfolds and is organised (Smith & Sparkes, 2009). Influenced by Bamberg's (1997) ideas about narrative positioning, which refers to how the 'self' is located in relation to others in the construction of a plot or storyline, the following questions were asked:

(i) What is the structure and plot of the story?
(ii) How are characters and narrator positioned in relation to each other within events?

Stage Four – Reading for performance (the narrative 'how' and 'why'). Stories are designed for the listener and identities are constructed in "shows" that "persuade" (Riessman, 2008, p.106). Consequently, the questions asked of the text were

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influenced by other authors approaches to 'how' a story is told, and the performance of identity (Goffman, 1959; Riessman, 2008; Smith & Sparkes, 2009):

(i)   What and how is language and emotion used in the storytelling, and why?
(ii)   Why does the narrator position themselves, others and the audience in this way?
(iii)   What is left unsaid or silenced? What might be the untold stories? (McAllister, 2001)
(iv)   How is this story co-constructed?

Stage Five – Reading for context. "Stories don't fall from the sky they are composed and received in contexts" (Riessman, 2008, p.105). In stage four, reading of identity performance was focused primarily on the individual's interaction with a smaller system (researcher, family and community); in this stage, the same questions were considered but with a focus on wider contexts of social, political and historical influences.

Stage Six - Comparing and contrasting across narratives: All five stages outlined above were completed for all the stories. Each story was then reviewed for its main themes and an overall impression was written. The married couple's stories were analysed separately. No attempt was made to compare across each story. Only a collective review of all accounts was undertaken to identify any similarities and differences in all the stories. This enabled me to provide the reader with a collection of broad emerging stories across the accounts, from which different positions in content, performance or context could be considered. Examples of working transcripts have been provided, full transcripts are not provided to preserve confidentiality (see Appendix 13).

3.6.4. Representation of stories

"Selecting the appropriate form in which to present a narrative inquiry requires careful consideration" (Riessman, 2008, p.192). The choices I made in regard to the 'writing-up' of the stories told by the five parents have been greatly influenced by Saukko (2000); she represented her own narrative work informed by a metaphor of embroidered and patchwork quilts. Embroidered quilts are made with "a centre and…develop a continuous pattern throughout" whereas patchwork quilts may not have a centre, each patch being individual but collectively creating a colourful and

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united whole (p. 476). Consequently, each parent's 'rich and textured' story or 'patch of the quilt' will be presented through my overall impression of the story, this is followed by 'stitching' them together by presenting emerging stories which occur across narratives.

I have chosen to predominately use third-person prose but combined this with direct quotes from the interviews, my own personal reflections and academic ideas. I have chosen this approach as writing in the third-person makes my position as an outsider to each story clear and provides space for academic voices, yet my own voice can also be heard. This approach is informed by Saukko (2000, p.303) who suggests the "voices of the author and the characters are always entangled with one another and are shot through with social voices that speak through them".

3.6.5 Reflexivity

For a post-modern perspective the process of reflexivity is crucial, and asks the researcher to make "plain, how he or she is positioned to understand the meanings of the participants" (Josselson, 2004, p.11). To ensure reflexivity was an active process a reflective journal was used to capture thoughts and reflections throughout, with particular attention to reflections after each interview and during data analysis (see examples in Appendix 12).

3.7 Rigour and credibility

A key feature of narrative is the concept of hermeneutic composability (Bruner, 1991) which refers to the imprecise process of a reader interpreting a text. Bruner suggests the best a writer can hope "is to provide an intuitively convincing account of the meaning of the text as a whole in the light of the constituent parts that make it up" (Bruner, 1991, p.7). Consequently, material provided by participants, which is then re-told by the researcher, is not viewed as being objective but permeated with subjectivity; this makes the process of 'validity' and 'reliability' challenging and some theorist would contest the relevance of these concepts within the more radical realms of this paradigm (Madill, Jordan, & Shirley, 2000).

Fielding and Fielding (1986) argue that triangulation, a credibility method used by some qualitative researchers, may provide a "fuller picture, but not a more 'objective' one" (p. 33) as its goal is completeness not convergence. Consequently, I have

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chosen to follow Elliott et al.'s (1999) guidelines (see Appendix 11) in regard to the how qualitative data should result in 'resonance with readers'; "the material is presented in such a way that readers/reviewers judge it to have represented accurately the subject matter or to have clarified or expanded their appreciation and understanding of it" (p.224). To aid this process each anonymised transcript was read by one other researcher (two other doctoral researchers using narrative methods and my supervisor) to ensure that the global impression written for each story had 'resonance' for them as a reader. I met with each researcher to obtain feedback. Only one researcher reported a lack of resonance with one aspect of Mary's story which she felt was not captured in the global impression; I reflected on the feedback and agreed with her assessment subsequently making minor changes to Mary's summary story.

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Chapter 4. Findings and discussion

4.1 Overview

This chapter presents my interpretation of the co-constructed narratives of five bereaved parents and the stories told of their emotional relationships with surviving children after the death of another child. As outlined in section 3.6.4 the results will be presented in two parts. The first section introduces my overall impression of each parent's story which I have previously described as 'patches of the quilt' and will include some demographic information to help provide context to the reader. The second section begins to 'stitch together' the narratives using the 'threads' which weave through the narratives, the emerging storylines (Saukko, 2000). My constructions of the emerging storylines are presented with connections to academic literature and a consideration of how context influences the stories told. Continuing the metaphor, I hope to leave the reader with my overall impression of the quilt.

4.2 Introduction of participants and their stories

As already outlined, significant efforts have been made to anonymise each parent and identifying aspects of their stories (please see section 3.3.4). Four mothers were interviewed and one father. All parents' described their ethnicity as white British.

As the writer of the impressions, I would like to remind the reader what follows is my own construction of the stories told. My impressions are ultimately a reduction of the rich and detailed stories told by the parents and are restricted by the word limit of this thesis. I have endeavoured to capture the spirit and unique voice of each parent.

All direct quotes from the narratives are denoted by the use of a less *formal type face in italics*.

<u>4.2.1 June (55 years old)</u>

June's son James died when he was 18 years old. James took his own life.

June was married to Bob at the time of James's death. James was the eldest child from their marriage followed by a younger sister, Lily. June had been married previously and during this marriage had her first child, Molly. Molly was 21 years old and Lily 10 years old at the time of James's death. June and Bob separated following James's death. June told her story at the offices of the CBS office.

Overall Impressions of June's story

June told a story that grew in detail and description and contained lots of water based metaphor. June's story is one of a mother and her family struggling to cope with the death of a child, she describes "*trying desperately to keep them afloat*". Her story illustrates the ebb and flow of emotional relationships, guilt and coping in bereaved families.

June remembered how before James's death she was a mother who "*thought I had all the answers….it'll all work out fine in the end. But things don't always, do they*". After James's death, June describes the first year as being in '*shock*'. Towards the end of the first year she recalls attending a bereavement workshop and hearing a young boy talk about his experience of losing his brother: "*he stood up there and said that he had lost his parents for four years. That's how long it took for his parents to come back…to him*". Consequently June "*tried to remain conscious that… no matter how grief stricken you are or how terrible you feel inside, that actually your living children have to take priority. But it wasn't always easy to put into practise*".

June described her struggle to cope and "*that brings with it its own… its own problems because not only have you got everything that's caused you to get to that point, but you've then got the added guilt, the fact that you're not coping and you need to be coping and you know that by you not coping, your family are struggling. Actually that just heaps on you even more doesn't it*?" June

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explained that *"as a parent of a child who takes their life you've got enough guilt to sink a battleship"*.

June felt that if she did not cope, her daughters *'panicked'* as they felt *"just a little bit rudderless"*. Even with her awareness of what her children needed from her, June *"reached a point when I probably just couldn't absorb anything else"* and this resulted in her attempts to *'escape'* by keeping busy. *"That was the point at which, at which I'd decided I didn't really want to be married any more. But I think looking back that's all to do with you just can't deal with everything, so something has to go"*.

June describes how Lily had always been a child that worried and was dependent on her, but after James's death: *"I think at the time you like to think that what you're doing is coping and they're not seeing through it. But in actual fact when you look back in hindsight you know that they must have seen gaping big holes in what you were trying to do. And whether that for Lily meant she felt more insecure….and so made the anxiety worse I think probably it did…you know. So that made her cling on even tighter. So instead of giving her that little bit of independence that I'd crave for her, in actual fact by me…being a little bit absent, I was making it worse"*.

Lily went on to require professional support for significant difficulties with anxiety – *"she wouldn't go upstairs and have a shower, she wouldn't go up to the toilet on her own'. 'It has been one long road of her overcoming one challenge after another"*.

Now on reflection June feels *"children will survive…not having their meals cooked for them and placed on the table every night of the week. They'll survive if their washing isn't done. You know, every day like it used to be, you know it's not the end of the world. But actually if you can't meet their emotional needs then…what damage are you doing long term?"*

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June is driven to share her story to help other families as she feels that her family didn't get the support they needed – *"if as adults you're given the right support…at the right time, then you can hopefully support your children better".*

4.2.2 Louise (47 years old)

Louise's son Jack died when he was 17 years old. Jack took his own life.

Louise had Jack and his younger brother Toby during her first marriage. Toby was 15 years old when Jack died. Louise remarried when the boys were young children. She married Richard and had another child, a daughter Alice. Alice was 7 years old when Jack died. Louise came to the bereavement organisation's offices to tell her story and bought lots of family photos to help illustrate her narrative.

Overall Impressions of Louise's story

Louise told a rich, flowing narrative full of metaphor, reflection and emotion. It is a story with Louise's commitment to honesty at its heart as she wanted to help others, as she was helped – *"if I'd have had some literature that would have told me at the time that other parents felt the same, that were in the same position, I think it would have helped me to feel less…like an alien".*

Louise tells a story of travelling through *'the fog'* of loss and grief – *"to me for a while, if you can imagine driving in a car….I felt like I was driving away from my family….but I could still see Alice and Toby in the- in the mirror if you like but they were behind (pause) and I couldn't stop the car so I was just driving….away…but….maybe I got far enough and then (pause) turned round and came back, but by that time Toby's gone somewhere and I picked up Alice I think but…hopefully I can find Toby along the way".*

Louise's account is full of small stories and anecdotes to describe the places she has visited on her journey. She describes the landscape before Jack's death as being one where Jack *'ruled the roost'* due to his behaviours relating to his health needs – *"we all had to dance to Jack's tune because if you didn't…life became difficult".* This was a place where Jack's needs were prioritised – *"everything was about*

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Jack". After the birth of Alice this was also a *'happy'* place that Louise felt was "*too good to be true….the only fly in the ointment was Jack's problems"*.

Louise describes her reaction at Jack's death as *'disbelief'* and *'shock'.* She describes her initial reaction to Jack's death as a "*deep, really deep physical need"* to have Toby and Alice close – "*everything was about Alice and Toby….having them close was really important because…it was as though if they went out of sight I wouldn't see them again"*.

But then the "*fog came down and I just disconnected"*. While driving through the fog "*I didn't even want to be around them. I didn't want…if I heard them coming into the room I would get up and go…somewhere else where I could be alone, just with my thoughts"*. This was a place where the sound of her daughter's voice made her think "*shut up, will you just shut up talking"* and any demands for care from her children made her angry because she was needed. Louise describes it as a place where "*I wasn't sure I could survive"* and without her children perhaps she wouldn't have survived. In the fog Louise was preoccupied and obsessed with Jack, "*everything was about Jack, remembering him"*.

Louise then recalls, "*I just suddenly, it was almost like I woke up from a drunken stupor or something you know, like I sobered up". "I remember thinking it was like a real slap around the face…that…for so long I'd just walked and looked at the- my feet…and not up…. I thought I'm here and alive and well and right, now let's get back to what I was supposed to be doing which was being a mum and a wife and erm….you know….put- not put it behind me, you never put that behind you but (pause) er get back on track if you like". "I've managed to get back on track with Alice"* but with Toby "*our paths have really gone too far apart"*. Toby is in a place he feels his mother would have "*preferred it if it had been [him] that had died"*. Louise describes how the "*relationship has now broken down because of that fog"*, I "*disconnected from him and I think he's angry about that". "I think Toby emotionally is stuck at fifteen…frozen in time"* and now "*in his own*

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fog". It was easier to reconnect with Alice as *"I think she was too young to…understand that I'd disconnected…I don't get the feeling from her that she is aware that I disconnected from her"*.

Louise now finds herself in a place of reflection and *"hope that we…can be close again"* but until then she is happy to sit with the idea that if her relationship with Toby, now a young adult, has *"broken down and we can't fix it, then if he's alive then…I'll go with that"*.

4.2.3 Clare (in her 30's)

Clare's daughter Jessica died when she was just over 16 months old. Jessica died in hospital after having an accident in the family home.

Clare is married to Steve. They have two other children, Lucy and Liam. Lucy was around 8 years old and Liam 2 years of age when Jessica died. Clare came to the bereavement organisations offices to tell her story.

Overall Impressions of Clare's story

Clare told a tragic story of loss. Clare's story was light in detail and description which resulted in a narrative that sometimes felt fragmented, making it difficult to follow and appearing inconsistent in places. Clare told her narrative with an assumption that the 'hearer' already has some knowledge of her story often leaving thoughts and details unfinished or unsaid.

For Clare this is a story of coping and being able to *'carry on'* after the death of her daughter. *"I just think it's, it's just coping it's, well, you can't um (pause) you know, at the time you say to yourself why? Why did it happen? This that and the other, and you can't dwell on it all the time. You learn not to. Umm.. and there's things that you [can't] change, you can't, you just can't think like that..you know"*.

Clare begins her story by describing a busy family life with three small children. She recalls how she had to manage Lucy being at school, the younger two at home and juggling the demands of her family. One morning Jessica had an accident at home

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which resulted in her death. Jessica described the immediate time after Jessica's death as a time when her home was full of people; friends, family and a variety of professionals with varying demands. She recalls the experience of having the local newspapers *"banging on her door"* and having to manage the stories her daughter was being told at school.

She remembers *"everyone was in the house, crying, this that and the other, erm..and me and Steve would just be sorting the stuff out in the shed...... cos we just couldn't cope with just sitting there......just moping about; you just have to keep busy cos you're still trying to come to terms yourself"*.

She describes *"people would come round and cry and we'd be like 'oh it's ok, it's ok' and it was just like- and if you sort of think...I'm not really that a strong person..but you think-..um we just couldn't, we just couldn't cry when people had come round'. She later explains 'you want to, but you're like 'no' and it's learning to control your emotions isn't it as well I think. You learn to control it..and I think you learn to be a little stronger I think, yeah"*.

Clare explains that *"I'd done what I could do...and there was nothing else, you know, I could do...you know to save her"*. For Clare the experience of losing Jessica made her *"see things differently"* she goes on to explain *"it's just worrying about silly things ....you've got nothing to worry about it's just um..deal with it and get on with it..cos life is too short"*.

Clare tells a story of becoming closer to her daughter Lucy, and has consistently remained close to Liam, her son. She tells how she has become a *"bit more relaxed, you don't worry as much...you know as you did before because you don't know what's around the corner and what's gonna hit you sort of thing"*. However she also presents an alternative story *"I don't think I cope with things as well as...probably before I lost Jessica...I haven't got um (pause) I don't know it's just um...I get quite stressed, quite, anxiety..um I think more since I've lost Jessica. Um I do shout a lot at both of them cos they don't listen, don't do as their told,*

obviously it doesn't help shouting at them…but um yeah I do feel..I think it's me, hormones, you know as well"

Clare tells her story as a woman who valued her strength to *"carry on"* and control her emotions when she had to face with the experience of the death of her daughter.

4.2.4 Mary (in her 40's)

Mary's daughter, Paula died when she was 24 months old. She died at home in her bedroom following a short illness.

Mary had another daughter, Emma who was 11 years old when Paula died. Paula was a longed for child who was conceived after many years of fertility treatment. After Paula's death Mary and her husband tried again with the help of medical professionals to have another child. Daniel was born three years after the death of Paula. Mary told her story at her home surrounded by the toys of her toddler.

Overall Impressions of Mary's story

Mary told a story reminiscent of a shattered fairy-tale which turned into a nightmare followed by the subsequent struggle to put the pieces of the fairy-tale back together again. It is a story in which the narrator navigates her relationship to guilt and is motivated to tell others what she has learnt about coping with loss, responsibility, choice and control – *"stop having the guilt all the time", "everyone's different… there's no right or wrong with the whole process really. You do what you can…with what you have in front of you"*.

This is a story that flows, rich in detail and full of superlative descriptions. It is a story of a family who started out as *"very close threesome"*, mother, father and *"precious"* daughter; *"everything was about Emma"*. Mary put a lot of pressure on herself to be the *"the perfect all singing all dancing mother"*. Then along came a longed for second child, a *"miracle baby"*. After a *"perfect pregnancy"* Paula arrived, she was *"the happiest baby, the most well-behaved baby ever…just delicious"*. Not long after his arrival, Mary experienced severe post-natal depression.

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Mary described this experience as *"ABSOLUTELY the most scariest thing…….I felt completely out of control"*. She *"found it very hard to deal with Emma at that moment in time because I just didn't have (pause) I didn't have the (long pause) I suppose the emotional- I just….didn't have the patience"*. Mary described how Emma had been *"everything you know. Doting on- to then..I just wanted to be on my own actually"*. Around this time Emma became physically unwell.

After lots of investigations, Mary described how health professionals explained Emma's symptoms in relation to her own health, stating *"the relationship between Emma and I was so intense….she was feeding off me"*. Emma said *"when mummy's better, I'll be better"*. This is a story of mutual influence of mother and child. They both got better, and life was *"perfect"*.

Then when Paula was almost two years old, the *"silent killer"* arrived and life became a *"nightmare"*. Mary found herself having days when *"you just didn't want to be here…[when] the pain is SO horrendous"*. Mary *"couldn't cope"* particularly with Emma. *"I found her very, very, very difficult to cope with her and cope with my own grief as well"*. Mary kept busy and '*functioned*'. She found herself full of conflicting emotions - part of her felt *"if something happened to Emma…I won't be here"* but another part thought *"I could literally have locked myself away from her and just…been on my own and let her…live with Grandma cos I haven't got to deal with it"*. Mary was full of grief, anger, resentment and guilt.

Mary remembers feeling that Emma, sometimes described as a *"drama queen"*, was *"testing her"*. *"I did resent it, I did resent her for- you know, for putting me in that position"*. Mary recalls thinking *"she'd be much more empathetic…..but of course she was nine, how on earth would she get that"*.

The family then went on holiday where Mary realised *"nobody had any choice, she didn't have a choice. You know we have a choice, I have a choice….you know*

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to….to cherish what we have, I don't want my marriage to fail, I don't want Emma to hate me when she's older…I made a choice….I can't let anything else fail". It was time to *"pick up the pieces and put them back together again…start again".* Mary says now *"I don't think it's ever a finished journey….I think you just learn to live with it and you do the best you can".*

For *"sensitive"* and *"intense"* Emma life has continued to include periods of being physically unwell, for example when Daniel was born; she has also been bullied at school and has come to manage her feelings through self-harm. She is putting her own pieces back together by getting support from health professionals.

For Mary part of rebuilding her fairy-tale has been being able to provide Emma with a sibling, she says giving Emma a brother was *"the most important moment of my life"…* *"I don't want her to be on her own".*

4.2.5. Andrew (45 years old)

Andrew's son Max died when he was 24 months old. He died suddenly and unexpectedly after a short illness.

Andrew and his wife had a daughter Holly who was 9 years old when Max died. After Max's death, Andrew and his wife tried again for another baby. Oscar was born a few years after the death of Max. Andrew told his story at the offices of a bereavement organisation.

Overall Impressions of Andrew's story

This is a father's story of the death of his child. Andrew's narrative readily flows and is rich in description and detail. Andrew takes the position of a *"good citizen"* who has tried to do the *"right thing"* for himself and his family, and feels that by telling his story he is contributing to helping others.

Andrew tells a story of a committed and modern father who felt that *"being CAPABLE to handle your children I thought was correct and how it should be. And I think we could say that because of that I had a consistent and steady, steady bond".*

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He describes the process of having a child as *"a journey"* in which *"you hope their journey…gradually it takes them away from you"*.

The first few weeks after the death of Max were an "*absolute blur"* and a period full of utter "*disbelief".* "*You do feel that it's your job as a parent to keep your children..safe in that you should have the solution for everything"* but with death there is "*no fix"*, "*there is nothing that can be done because it is finite".* Andrew describes that early on he felt "*it's no good either one of us going off the rails…she's damaged enough now. You know she's been hit hard, like we all have, but she's nine, you know I'm forty. So you know I should be sort of wise enough and grizzly enough to battle through, but she's nine, I mean she needs her parents more than ever".* As a parent Andrew felt it was "*our job….to absolutely protect her and do ANYTHING we feasibly could to make sure that she wasn't going to be damaged".*

Andrew positioned himself as "*I'm a big you know indestructible man…….I had to take that on my shoulders, as the man of the house as the father, as the sort of pre- in an old fashioned sense……it was my job to sacrifice myself in the home..for Holly and my wife. To absolutely be there for them and to- and to support them and to make them feel secure and then I had, I had to take mine somewhere else".*

He did that by having his own professional support, "*I used to come out going well I've just paid sixty pounds to sit for forty five minutes, the woman has barely said a word to me. I've done all the talking…and crying……… it was probably the fifth time when I went and I didn't cry….and I was actually almost, it sounds awful, I was almost bored. Suddenly it just, it was as if…everything - not that everything had gone because there's still- but I was just flushed out".*

Andrew feels this is significant for him – "*the importance of ME sort of cleaning out and leaving stuff in a room somewhere, like a room like this with a person that I*

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didn't know". He brings this idea to life by suggesting it's *"a bit like being a mop and then you get- I got squeezed out and I was the last one to get, you know, sort of they squeezed their stuff and I mopped it up and then I was like the mop of last resort".*

He describes how he *"used to have to try and bottle it all up"* because his role in the family was to pull *"it all back together and give it perspective and try and move everything forward a little bit".* This role sometimes required him to *"draw on your reserves of patience…….we've come so far, don't…don't say anything……don't say anything you're going to regret".*

Although taking a position of strength and protection Andrew describes how his emotions have been *"very transparent and have been shared with Holly. And I don't know, I, I think that-…that, I hope that's helped her, to see that we're all affected by it, but we can all go on together, as a- as a unit. And we are, we are a bit of, bit of a unit, together, because it's like stronger together".*

On reflection Andrew describes how the loss of Max *"actually brought us closer together…..it can fling you apart…or it can bring you together and it will depend maybe on the characters of the people and how the parents react. You know I think the parents in the end set the tempo and the tone for what's gonna happen, not the child".*

4.3 The Emerging Storylines

As a researcher I was faced with a dilemma at this point; I had gathered five rich, detailed and complex stories of parental bereavement with much to tell the reader, providing greater context and understanding of the parents and their families. I had to return to the focus of this study's research question; consequently this section presents my construction of the emerging storylines in relation to the emotional relationship between parents and surviving children.

Before I present these collective storylines, I will spend some time thinking about the local context in which these stories emerged. The emerging stories are then stitched together, continuing the use of the quilting metaphor (Saukko, 2000), and then come to be understood through an interpretation of parental narrative identity and how this has been influenced by the wider contexts in which they were constructed.

4.3.1 Introducing the Emerging Storylines

Many of the stories told by bereaved parents used evocative metaphors of a journey through grief, describing the landscape and weather along the road. One weather metaphor used by Louise was the 'fog' of her grief. I have chosen to use these metaphors in describing the collective storylines, as it conveys the nature of grief described by parents. The 'fog' is changeable; sometimes barely visible, sometimes thicker but the road ahead can still be seen and sometimes it is so dense that parents are unable to see anything else, even their surviving children, who are often desperately trying to find them.

The 'thread' that weaved through the parents' narratives was a story of emotional connection and disconnection with their children as they journeyed through the 'fog' of grief. Figure 4 illustrates how the emerging storylines and the context in which they can be understood have been 'stitched' together. Although perhaps helpful for the reader to navigate this chapter, Figure 4 is presented with a caveat, as it inadequately captures the fluid and dynamic nature of the emerging storylines presented.
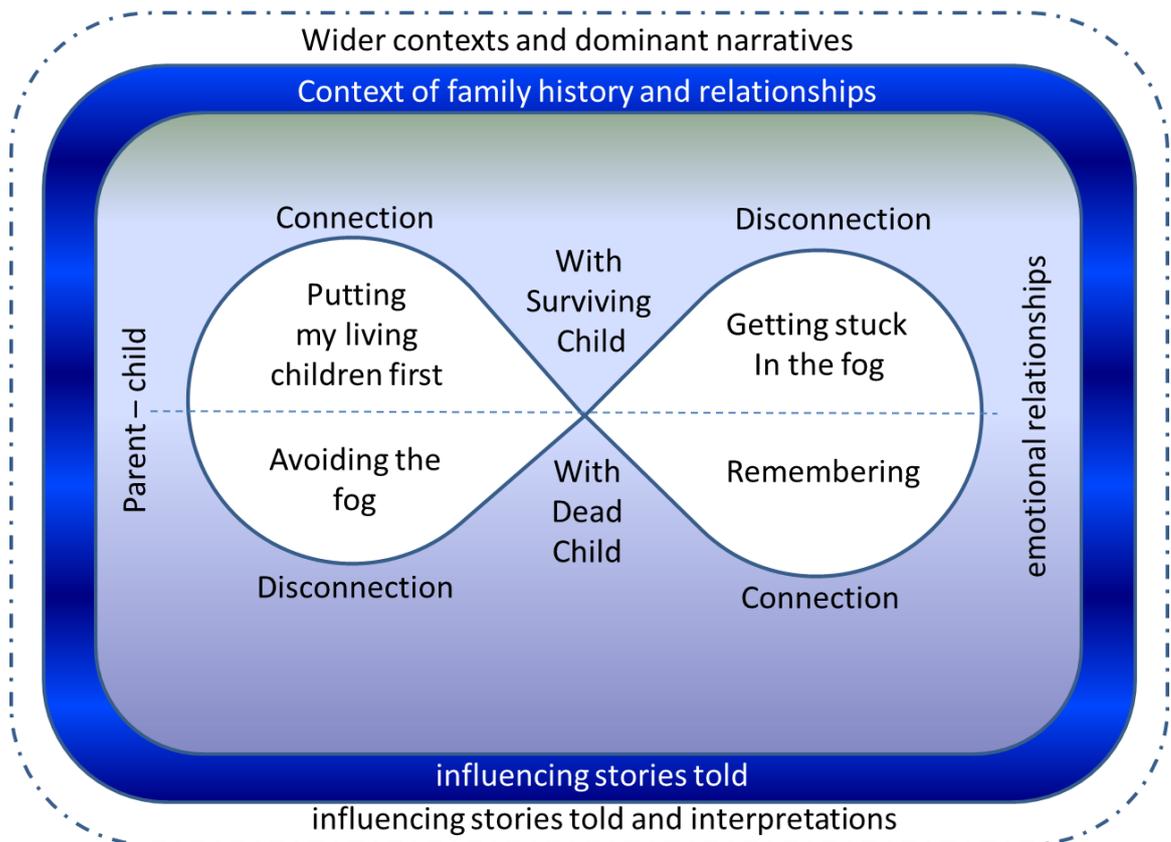
Figure 4: Parental journeys through the fog of grief: emerging storylines of bereaved parents' stories of their emotional relationship with their children

Parents told stories of connection (putting my living children first) and disconnection (getting stuck in the 'fog') with their surviving children during their journey in the 'fog' of grief. Stories of surviving children were intertwined with stories of connection (remembering) and disconnection (avoiding the 'fog') with the dead child. The stories parents told often contained multiple positions with fluidity between different aspects of the emerging storylines; for example, continuing to care for children (putting my living children first) whilst also grieving (getting stuck in the 'fog') with parents describing their parenting as just "functioning". Parents took different paths on their journeys. Some stories highlight fluidity with a shifting focus of attention and emotion, while others illustrated a more static picture of sitting more firmly within one perspective, for example getting stuck in the 'fog' for long periods of time. Many of

the stories highlighted the basic incompatibility and tension between 'grieving' and 'parenting'.

How parents journey through this terrain influences their surviving relationships. All the parents had stories about the 'fog', but for Louise, June and Mary these stories were more dominant.   Initially for Louise her focus was on the safety of her surviving children, but then the 'fog' fully descended and overwhelmed her. Later, as the 'fog' dissipated Louise tried to find her children; she describes how she was able to reconnect with her daughter, but is still struggling to find her son.

Mary and June told stories which were more dynamic and fluid, and recalled times when they found themselves in multiple places contemporaneously.   Ultimately, the 'fog' descended and they got stuck. For both, getting stuck in the 'fog' influenced them to 'get back on track'. They described complex and textured relationships with their surviving children.

Andrew and Clare told small stories of the 'fog', but soon moved toward a place of trying to 'avoid it' with rich narratives of being strong and putting their children first. They both talked of on-going connected relationships with their children.

The next sections will explore each of the emerging story lines and offer the reader my interpretation of why parents narrate their stories from these positions. However, I will begin by considering the context in which these stories emerged.

4.3.2 Context of family history and relationships

Bereaved parents told stories that could have been represented using a temporal flow; this is perhaps due the manner in which a traumatic event influences the telling of 'what was before', 'the event' and 'what came after'; perhaps it was due to the influence of the temporal order of the interview schedule; or perhaps because "storytelling is an indispensable human occupation" (Yorke, 2013, p. xviii).

The stories parents told were shaped by 'the event' of the death of their child which shaped the narratives of 'what came after'. However, 'what was before' is the landscape from which these stories are told. Story-tellers are "tangled up in stories of before" and these provide background and connection to a "vaster whole" (Wood, 1991, p.30).

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All the parents described their families' lives 'before' as full of 'normal stuff' such as school, birthdays, football matches and holidays; alongside a complex history of events which created their own unique family history. This history creates complex family structures resulting in an array of relationships. The stories told by parents have little in common, but they speak to the uniqueness and complexity of human relationships. This is illustrated by Louise when she reflects on the relationships in her family and says:

> *"the dynamics….are…what they are and sometimes you can't…help that. There are times when I- you know I've sat in a situation at a family party or something and thought (pause) this isn't what I want, I don't want Richard over there with Alice and me sat here with Jack, I want to mix it up a bit you know…but it always kind of fell back to…it fell back to…the easiest way…that things were…kind of like a default….position if you like. And I was conscious of not being happy about that sometimes"*   (Louise)

The complexity of the family environment and its context is rarely captured in the bereavement outcomes literature. Stroebe, Schut, & Finkenauer (2013) recently acknowledged that although bereavement research focused on the individual has expanded over the last twenty years, research at the family level has trailed behind. No research has been identified that examines parental grief and adjustment as an evolving process with consideration of the pre-bereavement environment (Arnold & Gemma, 2008; Alam et al., 2012).   Davies (1988, 1999) made attempts to quantify the concept of 'shared life space' between siblings pre-bereavement, but did not extend this to the family.

Systemic theorists argue grief should be viewed from a systemic level, as the individual sits within a complex array of relationships with family members, friends, community and society (Hayslip & Page, 2013; Walsh & McGoldrick, 2013). Systemic therapists propose that to help families manage their grief, they need to "be in balance or harmony with their past, not in a struggle to recapture it, escape from it,

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or forget it. We view therapy as helping families regain a sense of continuity and motion from the past toward the future" (Walsh & McGoldrick, 1991, p.7).

The context of the past and its influence on the shape of the family landscape is under acknowledged in the majority of bereavement research. The families' contexts have been presented in section 4.2, with their influence apparent in the development of the emerging storylines which will now be presented.

4.3.3 'Putting my living children first': connection to the surviving child

All the parents told stories of 'carrying on' in the 'fog' motivated by a connection to the needs of their surviving children. This collective storyline is illustrated by June who describes a story of a mother trying to put her *"living children"* first, *"no matter how grief stricken you are or how terrible you feel inside, that actually your living children have to take priority. But it wasn't always easy to put into practice"*.

As highlighted by June, 'putting my living children first' took place in the context of grief. For some parents, Louise, June and Mary, this was not a place in which they could firmly position themselves. However, Clare and Andrew told more stories of being able to put their 'living children first'. . The narrative identities that emerge from these differing positions will be considered later in this chapter.

Subplot: A reason to carry on

The interwoven and competing aspects of grief and restoration are illustrated by a subplot of surviving children giving parents a purpose. June describes how *"her needing me was a good reason to carry on"*. Mary recalls *"I suppose in a way….thank God I'd had her because that gave me a purpose to get up, get dressed"*.

Clare's story is dominated by her narrative of putting her children first and she recalls *"you know just carry on for him- and being…you know a parent as you do, and just carry on"*. Attending to the everyday demands of caring for children can help parents put the needs of their surviving children first. Clare tells a story of her active home life, acknowledging the demands of caring for her children helped her cope with the death of her daughter: *"Liam being as active as he always has been he's, he you*

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know kept me going. If I didn't have him…at home and just had Lucy at school..then I don't think I would have coped as well as I would have done'. Mary also spoke of how family routines helped her care for her daughter but described herself as '*just functioning*' implying that although connecting to some of her daughters needs she was doing that whilst also connecting to her grief.

June tells a story of trying to make her children happy:

> "*I can remember us all going hell bent on trying to make the girls' Christmas…as good as we possibly could I can remember spending a fortune you know, not that that compensates don't get me wrong but…you know you just want to see them smile don't you. You want to see some, want to make them happy and you know you can't make them happy, but actually even if you can do little things.. just to bring a little bit of a smile to their faces. And you know..we had lots of family… family times. We went away the following year, we had a really lovely week…umm (long pause) yeah..we had yeah. And the pictures show that we can't be miserable all the time".* (June)

Surviving children are presented as a motivation to 'keep going', providing parents with a reason to put their own grief to one side. Additionally in this process of caring and 'carrying on', parents may be 'distracted' from their connection to their dead child and the pain of grief. However, demands to 'carry on' are embedded within a parent's grief. When considering the wider social contexts and pressures in modern western societies on parents, particularly mothers, to put their children's needs above their own (Johnston & Swanson, 2006), it seems possible there is little space for an alternative narrative.

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Subplot: Protecting them

Part of the motivation for 'putting my living children first' appears to come from a collective story from all parents relating to their desire to protect their children.

Some are fearful of the potential 'damage' to their surviving children. Mary describes how "*all we could think- well all I could think about was how (long pause) you know, she can come out of this…in, in, in….sort of, with as less damage as possible*". Her narrative is mirrored by Andrew who tells a story of parental responsibility to limit "*the damage*" caused:

> "*you know we've still got a huge responsibility here. It's no good either one of us going off the rails…because what happens to Holly and we can't, she's damaged enough now. You know she's been hit hard, like we all have, but she's nine, you know I'm forty. So you know I should be sort of wise enough and grizzly enough to battle through, but she's nine, I mean she needs her parents more than ever*".
>
> (Andrew)

Andrew's uses words, such as 'grizzly' and 'battle' which evoke images of fighting against grief, although he is telling a story of protection. He goes on to describe his job as a parent *"was to absolutely protect her and do ANYTHING we feasibly could to make sure that she wasn't going to be damaged"*.

Although not always explicitly described, the 'damage' of which parents allude, is damage to surviving children's emotional well-being and future parent-child relationships. Parents worries were complex and varied for example, Mary was worried about her child 'hating' her in the future and Clare worried about the potential psychological damage to her son as he was at home at the time of his sibling's death.

Parents stories were motivated by a responsibility to care and love for their children, but they sit within a social and political context. Over the last few decades a neo-liberal 'grand narrative' has developed which 'emphasizes individual responsibility and self-management alongside a focus on managing risk' (Shirani, Henwood, &

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Coltart, 2011, p.2). Within this narrative, 'bad parents' are constructed as being responsible for various social problems originating from poor developmental outcomes (Hoffman, 2010).   These parental stories create a narrative identity of being a 'good parent', which is an identity that sits more comfortably in a society where 'the social standing of parents can be seen as contingent on child accomplishments and intelligence' (Shirani et al., 2011).

Another motivator for protecting children relates to some parents fears of surviving children also dying.   Although Louise found herself stuck in the 'fog' of grief for some time, her journey didn't begin that way, "*they were in the forefront of my mind in those early weeks and months*", "*physically having them close was really important because….it was as though if they went out of sight I wouldn't see them again".* She describes becoming "*obsessive about their safety*". Louise told a story of going on a day trip while on holiday and her son Toby chose to scuba-dive with other members of the family at the hotel.   Louise describes being privately consumed with a fear that she would be told Toby had died on her return.   On discovering Toby she said the relief made her feel physically sick.

"*That night, I couldn't stop looking at him…because I was so grateful….that he was- that he hadn't died*".   She also remembered "*walking up the road with Alice….in the village…really like imagining……..that a car would mount the pavement and….kill her".*   Louise felt that her worry made her controlling with her children and may have pushed them away at the time. Similarly Mary and June told smaller stories of anxiety and worry about the death of their surviving children.

These stories relate to Crehan's concept of the 'over protected child' where a parent's anxiety about the possibility of further losses means that the surviving child takes on a "heavy burden…..to make sure they stay alive, if not emotionally then physically. To bury another child, would be too much for their parents to bear" (2004, p209).

Before attending to the context in which these stories develop, I will present the next emerging storyline of 'avoiding the fog' as both these storylines appear to be interwoven and connected.

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4.3.4 'Avoiding the fog': disconnection from the dead child

All parents made varying attempts at 'avoiding the fog' of their grief; some parents avoided their grief infrequently and for some this became their preferred location. The collective narrative of 'avoiding the fog' is constructed from stories of 'keeping busy' or 'coping and being strong'; I would suggest it is underpinned by an unspoken motivation to avoid or disconnect from their grief and emotional connection to their dead child. This reflects Freud's concept of grief work being fundamentally about the survivor detaching from the deceased (Freud, 1917). Hedtke and Winslade provide an alternative construction termed "dismembering" described as "the processes that separate people from their bonds with each other in the wake of death" (2004, p.13).

Subplot: Keeping busy

The storyline of 'keeping busy' emerged for all the mothers. Clare told a story of her and her husband keeping busy:

> *"So everyone was in the house, crying, this that and the other, erm..and me and Steve would just be sorting the stuff out in the shed......, cos we just couldn't cope with just sitting there..um not be [?] just moping about you just have to keep busy cos you're still trying to come to terms yourself. You can't sit there and just cry and cry and cry".*
>
> *(Clare)*

This story of 'keeping busy' can been viewed as a story of escaping the high emotion expressed by friends and family. The DPM suggests that coping with bereavement is a complex process of 'confrontation' and 'avoidance', with 'avoidance' viewed as not necessarily detrimental (Stroebe & Schut, 2010). June tells a similar story, *"I just had to do everything, I kept cooking, I kept cleaning, I kept washing because that was my way of dealing with it"*. Again, Mary tells how she:

> *"couldn't sit still I was literally-...stupid things, you know I'd see a sausage on a television advertised but it was two*

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> *hours away and this amazing butchers so I'd get in the car*
> *and off I'd go. I just-…I couldn't sit still, you know I had a*
> *massive car crash, wrote my car off because, because I*
> *was so tired- I just couldn't-….my mind was just racing the*
> *whole time".*   (Mary)

Mary implies her mind is full of grief thoughts that need to be avoided; 'keeping busy' is a helpful strategy used by all the mothers. Although "persistent negative effect enhances grief, working through grief, which includes rumination, [which] has been identified as important in coming to terms with loss" (Stroebe & Schut, 2010, p.279). I have suggested that keeping busy is a way for parents to avoid their grief and connection to their dead child; however June describes how it may have also impacted on her relationships with her surviving children. *"I guess from that perspective the children didn't suffer from the care, the physical care side of it. Emotionally (long pause) mmm, I don't know".* This story illustrates the complex and relational nature of bereavement.

It is interesting to note that this was not a narrative that was dominant for Andrew. His lack of narrative may be explained by his story of getting back to work *"because you know I went to work and Holly went to school; my wife stayed at home. She had a huge gap in her life. I sort of, I didn't bury myself in my work, cos I think that's not the right expression, but I had something to focus on and Holly had to go to school".* Andrew's story reflects bereavement literature, in that fathers are reportedly more task-focused and generally go back to work earlier than mothers; however, a recent study suggests that post-bereavement fathers have a changed relationship to work and sometimes find it less rewarding (Alam et al., 2012).

Subplot: Coping and being strong

Stories of 'keeping busy' were presented as transient coping strategies but stories of 'coping and being strong' provided the narrator with a firmer footing. Andrew and

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Clare's narratives were dominated by stories of 'coping and being strong'. For June and Mary these stories were much thinner, and for Louise barely voiced.

Clare takes some pride in her position of strength and her ability to cope declaring, *"I feel I am quite strong and everyone said you know it's amazing how you know you've coped and stuff…"*. Clare positions her mother in an opposing role of 'emotional' illustrated by her story of telling her mother of Jessica's death, *"I rang her up afterwards and said to mum you know she's gone she was 'ohhhhh'. She just didn't..like accept it"*. When asked if she felt she had accepted Jessica's death she said: *"You know you have to. Um, I say you know..for the sake of my children..I think you learn to be strong for them and to cope and to carry on"*. Clare creates a narrative identity of strength shown through her ability to control emotions, cope and 'carry on' which she suggests is important for the sake of her surviving children.

However at the time of the interview and now, I am curious about the stories Clare did not tell and why she told a story of strength and coping. How do feelings of guilt or the experience of trauma shape her story?

Guilt is a common bereavement response and has been described as "a remorseful emotional reaction in bereavement, with recognition of having failed to live up to one's own inner standards and expectations in relationship to the deceased and/or the death" (Li , Stroebe, Chan, & Chow, 2014, p.166). Often these feelings are difficult to express as the bereaved become "locked in a struggle with his own conscience and unable to share such painful feelings" (Krell & Rabkin, 1979a, p.2)

How have Clare's possible feelings of guilt, responsibility and blame influenced the narrative identity constructed? Clare spoke very little about Jessica in her story but briefly mentions *"there was no way I could have saved her"* and *"I'd done what I could do";* in these declarations Clare is creating a narrative identity of 'not being to blame' but indicates her possible feelings of guilt about the circumstances of Jessica's death. This unspoken story is alluded too when Clare says *"at the time you say to yourself why? Why did it happen? This that and the other, and you can't dwell on it all the time. You learn not to. Umm.. and there's things that you*

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[can't] change, you can't, you just can't think like that..you know". Clare's unspoken story may be too hard to tell? Telling a story of strength and prioritising her surviving children creates a narrative identity of a 'good mother'. This identity perhaps protects Clare from her troubling emotions, and enables her to 'carry on' for her children whilst disconnecting her from Jessica.

Alternatively, or in conjunction, Clare's fragmented and sometimes difficult to follow story, could be an illustration of a traumatic memory. Traumatic memories often lack narrative coherence and are characterized by an inability to recollect important aspects of the event, repetitions and unfinished speech and thoughts (Brewin, 2011).

Like Clare, Andrew seems to ignore his own needs and takes on a position of father and protector which influences his decision to 'keep going'. For Andrew his position of strength comes from being a father:

> "I suppose…thinking I'm a big you know indestructible man like being a real man that I had to take that on my shoulders, as the man of the house as the father, as the sort of pre- in an old fashioned sense as the da- as the father, the husband, the- that it was my job to sacrifice myself in the home..for my wife and Holly. To absolutely be there for them and to- and to support them and to make them feel secure and then I had, I had to take mine somewhere else".   (Andrew)

Andrew draws heavily on his gender and his constructions of fatherhood and masculinity as motivators for putting his own needs to one side. Riches and Dawson suggest that fatherhood is associated "with images of protective masculinity, and bereaved father's may experience different pressure to 'limit' the impact of the death on their wives and surviving children" (2000, p.64). Other theorist have suggested that men are not "taught how to grieve in healthy ways, and in fact, maintaining the masculine role interferes with grieving" and is in conflict with their real feelings (Cordell & Thomas, 1990, p.75). Andrew's story embodies dominant societal constructions of fatherhood and masculinity.

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He goes onto describe the experience as *"it was a bit like being a mop…… you know, sort of they squeezed their stuff and I mopped it up and then I was like the mop of last resort"*. For me, this story creates a very different image; Andrew's metaphor as a 'mop' for his family's tears, feels like a description of himself as a piece of cleaning equipment that gets pulled out of a closet when needed, and then put away again. This image does not convey the same strength and masculinity he initially describes, and perhaps tells the audience something of his experience of sacrificing for his family.

4.3.5. Interwoven storylines: a dominant narrative of 'parenting' and an avoidance of grief

The emerging storylines of 'putting my living children first' and 'avoiding the fog' appear to be intertwined; both appear to relate to parental motivation of avoiding 'the fog' of grief enabling a prioritisation of the needs of surviving children. This appears to represent a connection to the surviving children and more of a disconnection from the dead child and parental grief.

As already suggested, the stories told by parents demonstrate a fluidity of movement through all the emerging storylines, however, some parents found themselves retelling a narrative which prioritises 'parenting' over 'grief'.

Narrative identities of being a 'good parent' appear to be shaped by parents' motivation to care, love and protect their children and their own relationship to parental responsibility; this sits alongside the additional motivations of avoiding feelings of grief, guilt, shame and a fear of future losses. Parents' narrative identities also appeared to be shaped by societal discourses of parenthood, gender and masculinity.

4.3.6 'Getting stuck in the fog': disconnection from the surviving child

Louise used the metaphor of the 'fog' to describe the debilitating aspects of her grief, she described how she had no control leading up to the first anniversary of her son's death and *"it was like a fog came down and I just….disconnected"*. All the parents had stories about the 'fog' but for Louise, June and Mary these stories were more dominant.

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June described herself as someone who had always coped before, but tells a story of her and her family "*sinking*". June continues with her water-based metaphor when she explains *"I don't think they ever felt… probably how they did during that year, which was probably…a little bit (pause) let loose, do you know what I mean if I say let loose. Just a little bit rudderless".* She tells a story of detaching from her children at times when she was *"particularly low"*:

> *"You always think don't you that actually there's no way*
> *your children will know how you're feeling because you're*
> *doing a really good job of covering it up, my goodness me*
> *I'm sure they see through you looking back".* (June)

She goes on to reflect *"whether the girls fell apart a little bit because I wasn't coping as well"* because *"if I wasn't coping….I think they panicked"* because if *"you don't cope, family don't cope".* June's story illustrates the interdependence in family bereavement.

For Mary, *"a year after she died I don't really remember an awful lot about what I was doing really……I think I just functioned"*, she recalls that she would get Emma up:

> *"in the morning you know giving her a cuddle……. not*
> *pretend cuddle but a sort of…doing a routine if you like,*
> *getting her dressed for school, taking her to school, doing*
> *my jobs….getting Emma back from school, making sure her*
> *homework was done you know, feeding her, doing all her-*
> *you know sort of- it was all very much a sort of….just doing*
> *a routine…just doing a routine, really".* (Mary)

Mary's story makes me curious about the story that Emma would tell about her mother during this year of 'functioning'; it evokes an image of a mother physically available but emotionally absent.

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Subplot: I can't cope with you too

Sometimes the 'fog' became so dense it meant that parents could not cope with the demands of others, particularly their children. Louise told a story of not being able to cope with her children:

> *"well if I'm totally honest with you...which I will be and it's difficult to admit but (pause) (begins to cry) (sniff) I didn't- I didn't even want to be around them. I didn't want- (pause) if I heard-...if I heard them coming into the room I would get up and go...somewhere else where I could be alone, just with my thoughts (sniff) so....Alice was very chatty...you know, young girl then and little girls talk a lot and I would- it would grate on me her voice even...and I used to be- I used to think shut up, will you just shut up talking (sniff) and Toby would come and ask (long pause) for something simple like I don't know....just you know, things that kids ask for...where his socks were or something and I would be- I would feel anger towards him, because he needed me and it was, it was all erm (long pause) I felt as though (long pause) I felt annoyed by their need for me, like if they needed dinner I'd think oh God I've got to cook, I've got to cook, and if it was only me, if it was just me I wouldn't bother cooking, I wouldn't you know, why have I got to cook".* (Louise)

Louise described struggling with these feelings for about a year. They resulted in her son, Toby asking if she would have *"preferred it if it had been me"* who died and not his brother. Louise explains *"I didn't parent properly in those-....in that year or so after....so I think...it's...the relationship has now broken down because of that fog".* Louise is brutally honest about her feelings for her children, perhaps

because she feels her actions were outside her control; it happened because of the 'fog'. Empirical research has suggested that bereaved mothers are less likely to believe they can control events that affect them, in comparison to bereaved fathers or a control group (Rubinstein, 2004).

Louise spoke of feeling like an '*alien*' and attempts to create a counter narrative by telling a story of another 'bereaved' mother who left her young children after her son died and moved to Scotland: "*and she was you know, she was a normal lady, she was- this was years before so she's fine now and she is back and I think she's got grandchildren now but (sniffs) you know, I think it's quite common to feel like that, to feel detached'.* Perhaps this story also allows Louise hope for the future, as this mother was able to reconnect with her family.

Mary told a story of not being able to cope with the demands of her '*intense*' daughter, who needed to be close to her, but:

> "*then she could also be really quite hideous as well. Umm….and I'd get very angry with her, very angry. Sort of- yeah. I think when you're grieving (pause) it's- and you've got a child, quite an emotional child, it's quite- it's quite intense and it's quite hard to (pause) I think the patience just goes actually".* (Mary)

Mary tells stories of feeling tested by her daughter feeling like "*you're making ME out to be the baddy here……she was testing me. And I did, I did resent it, I did resent her for- you know, for putting me in that position".* Positioning Emma's actions as '*hideous*' may allow Mary to 'rightfully' be angry with her daughter, absolving difficult emotions towards her daughter-. This story also illustrates the incompatible tensions between the demands of 'parenting' and 'grief'.

Clare didn't describe finding the demands of her children hard to cope with, it was dealing with other people's emotions: "*I can't cope with too many people um.. you know just being around and like that..umm, I find my mum..still now I can't sit*

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there..and talk about it with her……cos she is quite emotional..and I can't cope, I can't cope with that".

Whilst for June, it was when she was at her lowest point, *"I'd decided I didn't really want to be married any more. But I think looking back that's all to do with you just can't deal with everything, so something has to go".*

What these stories have in common is the relational demands placed on parents by other people, particularly children, which feel overwhelming. Boss' (1988) family stress theory suggests that the stress within families after death results in 'boundary ambiguity'; this is displayed when parents are physically present, but overwhelmed with their own grief, unable to offer support to other members of the family. The demands placed on parents can result in their desire to escape from them. .

Subplot: I need to escape

Andrew felt he understood how *"people [could] get absorbed by…..alcohol, drugs"* but explained that by *"the next morning you know you just don't feel in a, in a good place at all actually, very very emotionally down".* It was unclear if Andrew was talking about himself and if this was a common experience for him, as this was a story which contradicted a narrative of 'being strong'. However, research supports an association between parental bereavement and increased alcohol consumption; with Cacciatore and Flint (2012) reporting that the quarter of parents who indicated an increase in consumption after the death of their child got drunk on average 4.25 days a month.

For Louise and Mary their escape was more physical, Mary explained *"I could literally have just locked myself away from her and just….been on my own and let her…live with Grandma (pause) cos I haven't got to deal with it".* The physical distance is almost like a representation of the emotional detachment from their children and the need of parents to prioritise their grief.

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June kept herself physically close but used her emails as:

"my way of escape. So I would sit there in the evening and I would answer all my emails and...look really busy. Umm..and I think that might have looked to them as though I was not really there for them. Probably because I wasn't..there in reality. Yeah emotionally I was just, I just reached a point where I probably just couldn't absorb anything else".   *(June)*

Whilst Louise and Mary candidly express their desire to physically and emotionally detach from their children, June tells a story of being physically close but emotionally detached from her children using an escape that can almost be justified to herself and others. A story of hiding with email helps construct an identity of a 'good' mother still trying to be available, despite her own need to grieve.

Subplot: I can't carry on

Mary and Louise spoke frankly about their feelings of not wanting to carry on. Louise told a story of how at certain points:

"I wanted to die (sniffs) and....even though I wouldn't- I don' think I would have ever done it...because, because if I hadn't got Alice and Toby I don't- I wouldn't have survived it, I don't think. (Sniffs) But having them gives you a reason to carry on. But I did, I did get to the point where I....researched...you know, how you would do it, how many tablets it would take (sniffs) but then (long pause) you , you realise or you think of the pain that it would cause them on top of everything else and you can't- you have to put them before yourself. Cos I would never have, I wouldn't have ever put them through that, I love em too much".   *(Louise)*

Mary tells a similar story of having to carry on:

> *"but actually a part of you….wants to actually not carry on. You know wants to drive…through red traffic lights…and of course you know, what comes with that is such huge guilt….again guilt that….you know..days that you just didn't want to be here….because the pain is SO horrendous. (Long pause) But then having to- you know, but then having to think, God what's Emma going through, you know her- what's she feeling, what's her pain she's a child, you know. ……. I couldn't cope with her. I found her very, very, very difficult to cope with her and cope with my own grief as well, um".*   *(Mary)*

These stories illustrate the devastating and intolerable grief of parents. They paint a picture of parents who can get stuck, sometimes fleetingly, in their grief and how this impacts on their ability and capacity to cope with the relational demands of others, most particularly their children; although their children motivate them to 'carry on'. These stories show the untenable and incompatible nature of 'grieving' and 'parenting'.

However, Crehan (2004, p.215) asks the reader to "consider the experience of a child who seeks the comfort of her mother's arms having lost her sibling, to find those arms unavailable, or indeed broken, by the heavy weight of the dead child. I think that the danger lurks far deeper than lack of parental attention – the surviving sibling may encounter the emotionally 'dead' mother". She goes on to explain how children in these circumstances are forced to "enliven an inaccessible or absent mother at the cost of their own vitality" (Crehan, 2004, p.215). These two positions highlight a fundamental dilemma which faces parents and children in grief, how to balance the needs of 'self' versus 'other'.

Before attending to the context in which these stories develop, I will present the reader with the next emerging storyline of 'remembering' as both these storylines appear to be interwoven and connected.

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4.3.7 'Remembering': connection to the dead child

Remembering is about the "relationship going on and it is about what might continue rather than what might be lost" (Hedtke & Winslade, 2004, p.5). Remembering the child that was lost was perhaps only a spoken story for Louise, but as it was dominant in her narrative I felt it was important story to tell, and consider why it was unspoken in by other parents.

Louise arrived at our meeting with photographs, a list of things she wanted to say and an openness and readiness to say it. I felt she wanted me to 'see' Jack and understand her story. She told a story of obsessively remembering him:

> *"collating old photographs and.........I just buried myself in....um....obsessively remembering him......Spending every evening for hours 'til three in the morning on the computer reading, you know........and..and left, and abandoned them really".*

The time spent '*obsessing*' about Jack meant "*I didn't have the emotional energy to (pause) do whatever was necessary for Alice and Toby the next day because I was just zombie-fied*".

The DPM model (Stroebe & Schut, 1999) would suggest that 'remembering' is an aspect of loss-orientated coping and necessary in the bereavement process. Continuing bonds theorists would suggest that 'remembering' provides "solace" as the "inner representation of the child remains a real living presence in the parent's inner and social world" (Klass, 1993, p.360). While for mental health professionals the presence of 'persistent yearning' and 'preoccupation' a year after Jack's death, would lead to a diagnose of Persistent Complex Bereavement Disorder (PCBD) (DSM-V; APA, 2013). Research suggests that strong continuing bonds are associated with higher rates of distress, but only when the survivor is unable to make sense of their loss which is generally more problematic for parents (Neimeyer, Baldwin, & Gillies, 2006). Therefore, parents may experience stronger continuing bonds, which may result in higher levels of distress.

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However, Hedtke and-& Winslade (2004, p.22) have suggested that in western societies successful grieving "is measured by the responses and coping ability of persons and by how well they readjust to life after death. By contrast, the process of remembering is pathologized as a 'fixation', not unlike a neurosis. It is hardly encouraged". Perhaps this helps explain why this narrative is not found in other parents' stories.

Remembering can also be expressed in other ways. Louise explained that she went on to develop a strong connection to Jack's step-sister Imogen, which she found really helped her *"although she's nothing..blood relationship" "I feel a real bond with her. Because also she really looks like him…you can see………I mean I sort of love her fiercely…. I feel that kind of.. bond, bond with her now…since Jack died".* This story mirrors Crehan's 'replacement child' concept which posits that "a living child is elected as the embodied representation of a dead child. Some children are conceived specifically for this purpose; from the moment life begins they are consciously and unconsciously compared to a child that no longer exits and is invariably idealized" (2004, p.206).

Andrew described how his wife wanted another baby. He explained *"someone who's never been through that could probably think well..what cos like you go down the shops and you, you know, you you break the TV so you just go and get another one. It's not like that at all, it's just the fact that you NEED to re-establish that emotional connection".*

Perhaps for Clare, who described Liam as being 'my baby now' following the death of Jessica and with June already identifying Lily as 'her baby', their desire for a replacement is not so strong.

For surviving siblings, it is possible that excessive 'remembering' or becoming a 'replacement' child for their parents, means they themselves do not get 'remembered'.

4.3.8 Interwoven storylines: an emerging story of parental grief and inability to parent

The emerging storylines of 'getting stuck in the fog' and 'remembering' seem to be intertwined; both appear related to expressions of grief and impact on parents

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abilities to prioritise their surviving children. These stories represent a connection to the dead child, more disconnection from surviving children and challenges of bereaved parenting.

As already suggested, the stories told by parents demonstrate a fluidity of movement through the emerging storylines; however, some parents found themselves visiting and retelling narratives which demonstrate a need to 'grieve' over a need to 'parent'.

The 'grief' stories told by parents counterbalance the stories of 'parenting'. The 'grief' narratives were often positioned as being out of the individual's control which may reflect a societal discourse of the bereaved in a 'somewhat passive, suffering role'; with permission given for "time to grieve but the expectation is that this time will pass and that the sufferer will reach a point of being over the grief. Grief is thus allowed as certain period of emotional indulgence before 'moving on' is expected" (Hedtke & Winslade, 2004, p.34). Perhaps this discourse influenced Louise's description of her grief experience as feeling like an 'alien'.

Societal discourses construct 'grief' as an inevitable 'natural reaction' which removes any consideration of the influence of social and cultural context; with the grief experience constructed as "an individual psychological one rather than a relational or communal event ('you may need to be alone')" (Hedtke & Winslade, 2004, p.34).

However, these stories highlight the interrelated bereavement experience of parents faced with their own grief needs alongside the on-going needs of the other, their children. The interrelated nature of bereavement, particularly after the loss of a child, is a story not often heard. However, systemic theorist have suggested that "individual distress following loss is not only due to grief, but it is also a consequence of change in the realignment of the family emotional field" (Walsh & McGoldrick, 1988).

4.3.9 'Getting back on track'

> "When your son dies or your daughter dies, that's it, there
> is no fix. You can't..there's no meeting to be had, there's
> no phone call, there's no apology, there's no mmmm……..
> there's nothing that can be done because it's finite. And
> you know I think that's difficult because we all like to

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> *control…we all think we can control um quite a lot about what happens in our lives but you actually sort of realise that actually you are in control of very little"*   (Andrew)

Parents talked about death as something that could not be controlled; however, they told differing stories of 'choice' and 'control'. Andrew and Clare told stories of taking 'control', while others told stories of having 'no choice' over their grief. 'Choice' and 'control' is a thread that weaves through parents' stories of 'getting back on track'.

For Andrew early on in his narrative he explains:

> *"I'm quite pragmatic and, and I think quite down to earth and… just decided it was up to us. You know it was our life so we've got the rest of our lives in front of us and we've got Holly and we've got each other". "And the right thing to do is…to make it work, you know is to is to be good citizens and to..(sighs) to try and make the right steps"*
>
> *(Andrew)*

An alternative narrative was told by Mary about going on holiday after a difficult family time, this was a *"breaking point for us"* as it *"brought us all back…together"*. For Mary it was about making a choice:

> *"you know Paula dying didn't- nobody had any choice, she didn't have a choice. You know we have a choice, I have a choice….you know to….to cherish what we have…because you know, I don't want my marriage to fail, I don't want Emma to HATE me when she's older because I didn't deal with this properly (pause) or I was bad to her- whatever…I didn't want her…to resent me in any way. And you know she'd already lost her sister….I'd lost a child, she'd lost*

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> *her sister.........You know we owe it to her and actually we owe it to ourselves, I mean we owe it to Paula"*
>
> *(Mary)*

For June, the turning point came at her lowest point and she recalls *"I promised myself I'd never ever get to that point again. I would never ever allow myself to feel…that way again. It was not ever going to happen and it hasn't".*

While Louise she tells a story of waking up:

> *"I just suddenly, it was almost like I woke up from a drunken stupor or something you know……….And then suddenly it was- I remember walking one day with the dog and thinking (pause) 'it's beautiful' and you know I hadn't thought that for such a long time. You know the scenery and the fields and the sky and everything and I remember thinking it was like a real slap around the face…that…for so long I'd just walked and looked at the- my feet…and not up. So that was…that's a really sharp memory and I, it's…over the space of a few weeks, it was as though….I thought I'm here and alive and well and right, now let's get back to what I was supposed to be doing which was being a mum and a wife and erm….you know….put- not put it behind me, you never put that behind you but (pause) er get back on track if you like".*
>
> *(Louise)*

Post-modernist thinkers would suggest these stories reflect the context of a neoliberal modernist society that individualizes grief and promotes the idea of "productive, consuming citizens"; as such, expressions of grief are "considered a failure to adapt to this modern, happy and productive society. The only solution to this problem of adjustment is to seek professional help and get back on track" (Granek, 2014, p.62).

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4.3.10 Competing stories of 'parenting' and 'grief'

It is possible to construct the parents' stories of 'putting my living children first' and 'avoiding the fog' as narratives of 'good parenting', whilst the stories of 'getting stuck in the fog' and 'remembering' are narratives of the 'bereaved parent' (see Figure 5). In essence, parents told stories about the competing demands of 'parenting' and 'grief'.
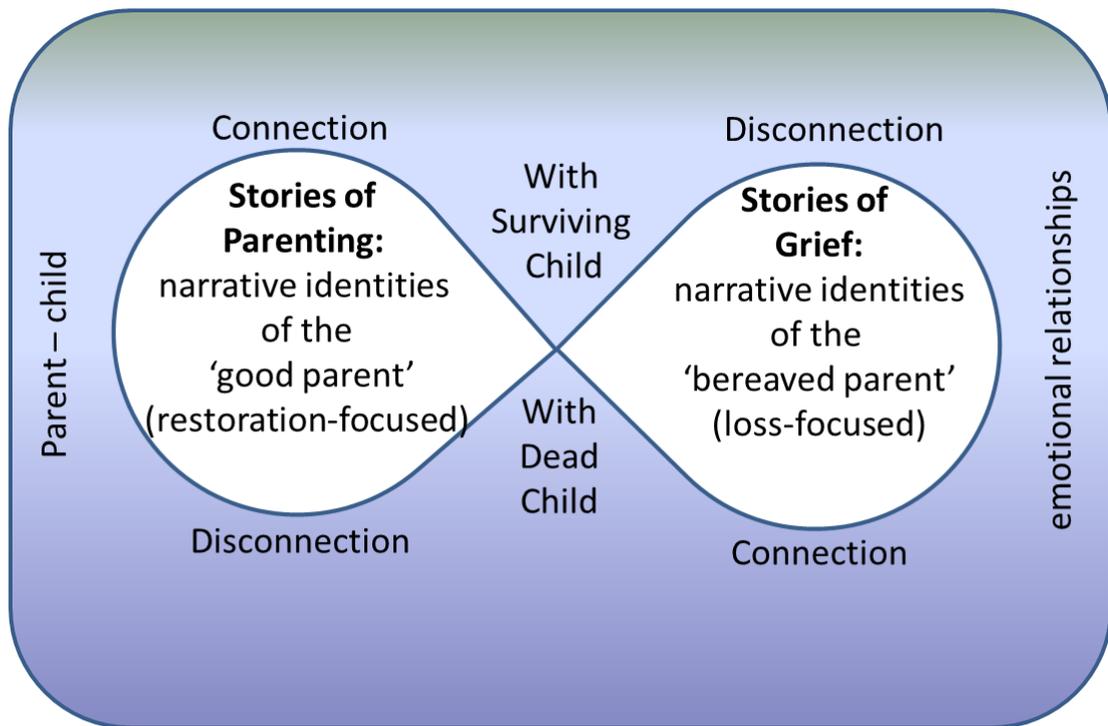
Figure 5: Competing stories of 'parenting' and 'grief'

These competing narratives of 'parenting' and 'grief' may qualitatively reflect the Dual Process Model (DPM) (Stroebe & Schut, 1999), although the DPM focuses on the bereaved individual and their 'oscillation' between loss orientated ('getting stuck in the fog' and 'remembering') and restoration orientated ('putting them first' and 'avoiding the fog') coping. However, this study has focused on the relational rather than individual aspects of bereavement and as such, moves away from an individual focus to a focus on relationships between parents and children (from the parent's perspective). This adds to the complexity of 'oscillation', as well as illustrating its

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relational implications. The stories parents told were found to be more fluid and interwoven, moving through times of restoration and grief, and were underpinned by the demands of and connections to their children. Furthermore, the findings highlighted that 'oscillation' has implications for the parent-child relationship and child well-being. Therefore, the results highlight the importance of considering a relational and contextual understanding of grief.

Another way to consider the implications of these competing storylines is through the construct of 'continuing bonds'; more specifically the competing demands of parental connections to both living and deceased children. Parents' told stories of grief that resonated with the idea of 'continuing bonds', a "ongoing inner relationship with the deceased person by the bereaved individual" (Stroebe & Schut, 2005, p.477). However, some parental stories implied that when connecting to their continuing relationship to their dead child, they lost a connection to their living children. A review of the research literature in this area suggests 'continuing bonds' can sometimes be helpful and sometimes harmful; in this study parents at times told compromised stories of parenting within the context of adopting the identity of grieving parent. Stroebe and Schut (2005) suggest that some bereaved people who struggle to "adjust" may need to work at "loosening" their bond and "relocate" their loved one (p.490).

Ultimately, Figure 5 illustrates the conflicting demands on parents to attend to the emotional and physical needs of their surviving children (restoration) or attend to their own grief for the child that died (loss). How parents navigate this terrain is highly complex, poses great challenges and potentially has significant implications for the parent-child relationship and well-being of the child. Furthermore, it has direct implications for clinical practice (see 5.3.3) and is influenced by individual, family, cultural and societal factors.

Grief is universal but its expression is culturally, historically and politically located (Granek, 2004). Grief theories become part of societal discourses and "through the development and deployment of psychological knowledge, we produce identities for people and then squeeze them into performances of identity that fit a given social norm. Thus, the production of 'normal' and 'natural' grief responses gets built into the production of the normal and stable good citizen of the modern national state" (Hedtke & Winslade, 2004, p.39); for example, Andrew's narrative of a 'good citizen'

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illustrates these ideas, alongside his narrative identity which is shaped by dominant discourses of masculinity and fatherhood.

This study highlights the need for a relational construction of bereavement, which is juxtaposed to the privileging of the individual within the modernist paradigm. Modernism emerged alongside a decline in religion, and "whereas it used to be the case that religion and traditional societies offered social processes around mourning that provided rituals and practises to deal with death and grief, the modernist focus on the self has left people bereft of meaning, community, and structure with which to manage grief and has placed the onus of responsibility for managing one's feelings on the individual self" (Granek, 2014, p.62).

These ideas are evident in the societal discourses of 'intensive mothering' Hays (1996) which Johnston & Swanson (2006, p.510) define as a "child-centred, expert-guided, emotionally absorbing, labour intensive, financially expensive ideology in which mothers are primarily responsible for the nurture and development of the sacred child and in which children's needs take precedence over the individual needs of their mothers". This construction of motherhood, alongside the political discourse of parenting as a 'public health issue' - illustrated in a statement made by Nick Clegg[6] stating "parents hold the fortunes of the children they bring into this world in their hands" (Dermott & Pomati, 2015) – provides compelling pressure for parents' to construct narratives of 'good parenting', put needs of their surviving children first and quickly work through their grief.

Ultimately, a focus on the individual parent removes consideration of family, community and society. This focus can have implications for bereaved families, as wider systems can play a larger role in supporting surviving children as parents 'battle' to cope with their grief for their deceased child. A fundamental postulate of systemic thinking suggests that difficulties do not need to be viewed as 'either/or' but can be approached from the position of 'and/both'. The stories parents told sometimes felt located in 'either' being in one place or another - grief or parenting - but many of the stories told represented the struggle of being in 'both' at the same time. This idea would suggest that parental bereavement does not have to be viewed as 'grief' or 'parenting', but both; not just a personal experience of loss but an

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[6] UK Deputy Prime Minster until May 2015

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experience of family. Sometimes one experience dominates, but grief has fluidity, movement and complexity and multiplicity.

4.4 Unheard stories of the children

Although the parents told many stories about their surviving children it often felt that their stories had been unheard and untold. This is idea is reflected in a story told by Louise:

> *"If you can imagine driving in a car….I felt like I was driving away from my family….but I could still see Alice and Toby in the- in the mirror if you like (starts to cry) but they were behind (pause) and I couldn't stop the car so I was just driving….away…but….maybe I got far enough and then (pause) turned round and came back, but by that time Toby's (sniffs) gone somewhere and I picked up Alice I think but…hopefully I can find Toby along the way" .*
>
> *(Louise)*

What stories would children tell? Their stories were not the focus of this research project but I feel it is important to draw this chapter to a close by attempting to locate the children and their relationships with their parents (through the lenses of the parents' stories), now the parents feel they are 'back on track'.

4.4.1 June's daughter - Lily:

June described Lily as *'loving'* and *'affectionate'* who had *'always been a worrier'*. June never lost sight of Lily, even when her marriage failed and suggests that *"I….probably didn't foster enough independence, but she was my baby"*. Lily's *"anxiety just..quadrupled after James died". "She became increasingly more anxious as time went on. So….the separation anxiety became a huge, huge issue to the fact that she wouldn't go upstairs and have a shower, she wouldn't go up to the toilet on her own'. Lily was completely….unable to function if she was away*

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from home or me". During her grief June became less emotionally available for Lily and June felt *"that made her cling on even tighter. So instead of giving her that little bit of independence that I'd crave for her, in actual fact by me...being a little bit absent, I was making it worse"*. June tells a story of an inter-dependent relationship with Lily which may have functioned as a source of comfort for June during her marriage difficulties; I wonder whether a story of anxiety would have been told even without the death of James.

Lily began to have therapy to help her anxiety and June feels that she continues to work really hard and has won many '*battles*' against her anxiety. *"I guess when you look back it all fits doesn't it but you can't see that at the time"*.

4.4.2 Clare's children - Liam & Lucy:

Clare said she always felt close to her son Liam, and felt she never lost sight of him. Liam was with Clare on the day of Jessica's accident and she tells a story of worry about Liam's 'difficult' behaviour and whether it has been influenced by the death of Jessica or just being a 'boy'.

Because of her worries for Liam, Clare tells a story of how Liam has been 'spoilt':

> "*he gets away with murder half the time and now we're paying for it (laughter). No, I think he's been, he's been spoilt because..obviously everything that happened, has got away with a lot of things and my mum spoils will spoil him. Now obviously we're paying for the price of it because he can be a handful. But I think every child is..you know, they do push the barriers don't they"*.   (Clare)

Lucy was the eldest of Clare's children, and Clare tells a story of Lucy being given lots of attention before her brother and sister arrived *"but obviously when, before Liam and that were born she had all that attention....and then she had nothing"*. Clare told a story of Lucy wanting her own space which may explain her being in her

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room, rather than possible alternative understandings, for example Lucy may perhaps feeling she didn't have a 'space' in the family.

After Jessica's death Clare tells a story of how she spent a lot of time talking with Lucy, *"I just remembered sitting on her bed and her crying......and yeah just telling her she can ask me anything, be open, it doesn't matter if it's gonna hurt me or make me cry cos it's good to cry and then she would cry, she'd get upset"*. Clare allows her child to have an 'emotional' identity but not herself or her own mother. Clare tells a story of being around more for Lucy after Jessica's death, and being closer because of it.

4.4.3 Louise's children – Toby and Alice:

Very early in the interview Louise tells how Toby has *"made a real mess of things"*, positioning Toby as the source of his own difficulties. Louise goes on to tell a story dominated by her first son Jack, which is illustrated by her difficulty inrecalling past memories of Toby. Louise describes Toby as a *"perfect child"* as a young boy. Louise explains how her time and energy was taken up by Jack who was a child with special needs. Toby was *"really undemanding and just used to- I think maybe inside right from when he was born he knew, well I've just got to get on with it cause my mum's busy"*.

Louise tells a story of how she *"abandoned"* her children after the death of Jack. For Toby, *"I think he would feel, I think he would say that I just....um, that I abandoned him, disconnected with him and I think he's angry about that"*. Louise tells how what see sees as Toby's sense of abandonment resulted in him feeling like he should have been the one to die. *"Emotionally [he] is stuck at fifteen I think, that's why he's turned to drugs, I think he's- he hasn't really- he's frozen in time"*.

Today their *"relationship has broken down now"*, *"it's really grim"*. Louise feels *"I failed- like I failed him (crying) sorry, I didn't think I'd get this upset"*. Louise is currently afraid for Toby's safety because *"he does get himself into all sorts of-*

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he's been arrested several times, and got into all sorts of scrapes" . The story Louise tells of Toby evokes the sibling bereavement responses defined by Davies (1999) of "I don't belong" and "I'm not enough" which are associated with relational difficulties in the family.

Alice's story is not as dominant as Jack and Toby's which perhaps reflects her position in the family. Louise has limited memories of when Alice was first born which Louise suggests is because of the demand of Jack at the time. Louise describes Alice as being *"easy to be close to…. very tactile and loving and….cuddly and kissy and…tells me she loves me all the time..and she's always been like that".* Louise explains that as Alice was the third child and so *"she would have to fit in with everything, but she was easy to (pause) you know she accepted that".*

Following Jack's death, *"Alice wasn't sleeping at night and having nightmares, and wouldn't get in the car, cos she thought the car was gonna crash"* , at that point the family got professional support for Alice. Louise feels that reconnecting to Alice *"felt a natural process……maybe not, I might be wrong I don't know, but I don't get the feeling from her that she is aware that I disconnected from her. I think maybe she was too young'.* Louise also suggests to the reader that this may be because she's a girl.

However Louise tells a story of how Alice has found a way of connecting with her mother around the time of Jack's anniversary and gave her mother time to be alone, *"I thought that showed a real closeness…she understood me enough to know to put- she's only twelve and yet she put me before herself which I thought was really lovely…and um and we did we watched a film when we got back, when I got back and cuddled up and then didn't need to say any more you know".* The closeness which is implied in Louise's story, feels contingent on Alice supporting her mother's grief, rather than a connection directly with Alice.

From the stories told by Louise it is suggested that Toby is unable to be 'picked up' by his mother because of his resentment and anger, whereas Alice allowed herself to be picked up by her mum even though that connection is mediated by her mother's

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ongoing connection to Jack; perhaps this is a role that Toby is no longer willing to play.

4.4.4 Mary's daughter - Emma

Mary describes Emma as a *'very sensitive'* and *'precious'* child. After many years of fertility treatment and the birth of Paula, Mary suffered post-natal depression (PND) and she tells how *"you feel scared and you're scared about what you might do or (coughs) how you might act". "I just thought the more she was around me the more she was gonna be….I suppose in trouble if you like. So I just thought it would be better if Auntie Brenda had her quite a lot until- and obviously and I did get better fairly- I didn't have it for very long I probably had it for about six weeks quite severely"*.

However, Emma became unwell after her mother's PND. Mary recalls *"some parts of you feel really sorry for her because….God it's really affected her. But other-…and that's really sounding selfish, but at the time you just think actually Emma (pause) get a grip actually..and I used to feel quite at times slightly resentful because it's making me feel SO lousy as a mother..that I'm failing her. Because why would she be feeling like this"*.

Mary describes Emma as an *'intense'* girl but one with great qualities of generosity and kindness.Emma's health improved; however, Mary described how she has recently started to self-harm to help manage her emotions. Mary explains *"a part of you wants to shake her and go….Emma stop this it's absolutely ridiculous"*.

In their journey together, Mary and Emma developed a 'intense' relationships. Mary's description of Emma as being an 'intense' child; perhaps helps her cope with her feelings about the difficult parts of Emma's story which may not sit comfortably within a narrative of devoted mother and child.

4.4.5 Andrew's daughter - Holly

For Andrew, Holly's identity has been shaped by her experience of being an only child "*because she was an only child for s- for many years, she, she, she is quite needy and she always has been because she's been an only child. And I think only children, you know they're very used to getting a lot of one-to-one attention*".

Ultimately, Andrew feels that as a family *"we have shared the journey. And we've-we've made sure, we haven't left the stragglers behind between us"*. He describes himself as a father who has prioritised the needs of his wife and child, and this has enabled him to hold and sustain these relationships.

On this difficult journey a new child Oscar joined the family. Andrew describes how along the way Holly has held tightly to her parents, which he suggests is because she "*wanted to make sure that nothing else breaks or, or she doesn't lose anything else*".

4.4.6 Summary

These stories are constructions of the stories parents told of their children; the children's voices are still unheard and consequently any conclusions are difficult to make. However, these stories indicate that many of the 'surviving siblings' have experienced their own difficulties since the death of their sibling (self-harm, drugs, anxiety). The reasons why these difficulties emerged will be complex and multifaceted and may have emerged despite experiencing sibling bereavement. I would suggest problems emerged within the family and wider system, and are best understood in that context.

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Chapter 5. Final Discussion

This study sought to hear bereaved parents' stories of their emotional relationship with their surviving children. In this chapter, I offer my thoughts on the clinical relevance of the study and its implications. I will then present the strengths and limitations of this study, and offer potential ideas for further research, before closing with a summary of my personal reflections on the process. I will begin by presenting a summary of the main findings of the study.

5.1   Summary of Findings

This summary will address the study's main research question of 'how do parents story their emotional relationship to their surviving child or children after the death of another'? The research study's sub-questions were: what stories do bereaved parents tell about their emotional relationship with their surviving children over time; what influences this relationship and what stories do parents imagine their children would tell about their emotional relationship with their parents? Parents' answers to these questions are interwoven into the main research question and as such will be addressed within the main summary.

Parents told stories of connection and disconnection in their emotional relationship with their surviving children after the death of another child in the family. Emotional connection and disconnection is shaped and influenced by the competing and potentially incompatible tasks of 'parenting' and 'grieving'. Stories of connection with surviving children were constructed as 'putting my living children first' and 'avoiding the fog' of grief; these stories illustrated more disconnection from the deceased child and less connection to parental grief. Conversely, stories of disconnection with surviving children were constructed as getting 'stuck in the fog' of grief and 'remembering'; these stories illustrated more connection to the deceased child and more connection to parental grief (see Figure 4).

Parents' stories of connection and disconnection were sometimes static, sometimes fluid and often illustrated multiple positions contemporaneously. Many of the stories parents told emphasise the basic incompatibility and tension between 'grieving' and 'parenting'. The movement between connection and disconnection reflects the 'oscillation' mechanism described in the DPM of coping with bereavement (Stroebe &

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Schut, 1999), which suggests bereaved individuals move between times of loss- or restoration-focus, and times of detachment from both positions. However, parents' stories emphasised the relational aspects of bereavement which are not fully considered in this or many other models of bereavement.
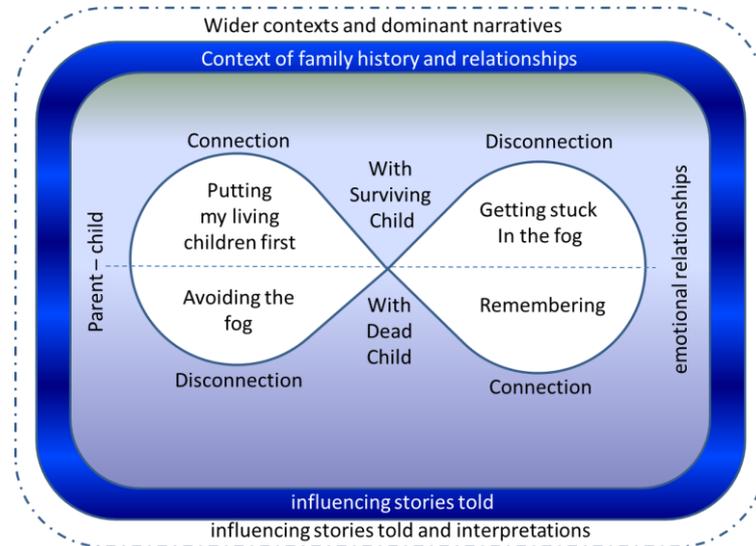
Figure 4: Parental journeys through the fog of grief: emerging storylines of bereaved parents' stories of their emotional relationship with their children

It is possible to construct parental stories of connection to surviving children as stories of 'parenting' and stories of disconnection from surviving children as stories of 'grief' (see Figure 5). The narrative identities that parents' create are shaped and influenced by past family history, family context and wider societal discourses.

Figure 5: Competing stories of 'parenting' and 'grief'

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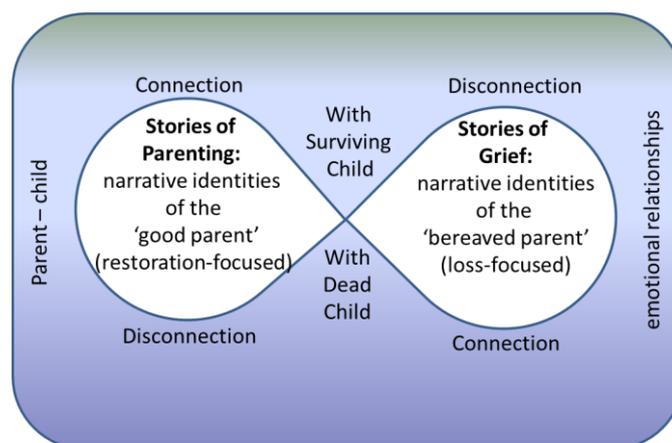
Two parents, Andrew and Clare, told stories which emphasised narrative identities of being a 'good parent'; however, these stories appeared to be particularly shaped and influenced by individual and family contexts along with societal discourses of parenthood and gender. Connections with surviving children appear to have been maintained, with grief and connections to deceased children less emphasised.

Two other parents, June and Mary, told narratives which demonstrated the more contemporaneous nature of 'parenting' and 'grief', illustrating the difficulties and demands parents face when trying to hold onto their connection with both their living and deceased children. Relationships with surviving children were maintained although both had struggled with emotional difficulties.

One parent, Louise told a story dominated by her family history and 'grief', creating a narrative identity of a mother controlled by her 'grief' for her deceased child. Louise's construction of grief reflects the societal discourse of 'grief' being natural, inevitable and something which one endures and emerges from, recovered. Louise's relationship with her eldest child is currently 'broken' and disconnected, and her son is struggling with emotional difficulties. Louise feels a connection to her daughter has been re-established, although enabled through a mutual connection to Jack, her son who died.

Parents' stories illustrated the relational and complex nature of family bereavement, influenced by multiple contexts and discourses which challenge the dominance of an individual focus in the bereavement literature. Whether parents privileged stories of connection to their surviving children or stories of a bereaved parent, there were implications for parental sense of self, their experience of their grief, their parenting, the parent-child relationship and the well-being of their surviving children.

5.2   Clinical Relevance

5.2.1 Shifting bereavement theories and interventions from the individual to the collective

"Bereavement theory and research have focused primarily on individual grief in the loss of a significant dyadic relationship with insufficient attention to the impact of a death and loss on the family as a relational system" (Walsh & McGoldrick, 2013). This study highlights the need to develop new interventions using a relational

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perspective, as well as inform and develop bereavement theories, such as the DPM model (Stroebe & Schut, 2010) and 'continuing bonds' (Klass, 1993). This is particularly important when considering the importance of the parent-child relationship and family environment, and its influence on a child's development.

One relational approach is systemic therapy (Becvar & Becvar, 1988; Boscolo, 1987). A systemic perspective allows for a consideration of individual and multiple perspectives including historical, cultural and social contexts, whilst also acknowledging the individual, unstructured process of grief which may never be 'resolved'. Systemic therapists Walsh and McGoldrick (2013, p.21) suggest that bereaved families can be supported in adapting, through "shared acknowledgment of the death and loss"; "shared experience of loss"; support in "reorganization of family system" and working towards "reinvestment in other relationships and life pursuits".

A systemic perspective can also take fuller consideration of differing positions of family members; exploration of these positions may allow more flexibility and freedom within the family system, for example, allowing father's more space to grieve and opportunities for siblings to participate in family grief without feeling the need to protect parents.

5.2.2 Consideration of influence and impact of pre-bereavement family environment

This study has highlighted how the pre-bereavement family context makes an important difference to how death is understood and how different family members subsequently react. Therefore in order to fully understand the meaning of the death it is vital that practitioners enquire about the family before the bereavement, in order to better understand the impact of the bereavement. Again, a systemic perspective is well placed to help "re-appraise family history, replacing deterministic assumptions of causality with an evolutionary perspective. Like the social context, the temporal context provides a matrix of meanings, in which all behaviour is embedded" (Walsh & McGoldrick, 1991, p.7).

5.2.3 'Not being an alien' - giving voice to the unspoken experience of 'bereaved parenting'.

Guilt is a commonly experienced emotion for bereaved parents (Li et al., 2014). In a space of grief, guilt and continuing parenting - shaped by a societal discourse that

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'bad parents' are responsible for an array of 'social ills' (Shirani et al., 2011) – there is little room for bereaved parents to explore their contradicting and at times troubling experiences (e.g. in relation to parenting their surviving children), alongside developing an integration of 'grief' and 'parenting', as demonstrated in this study.

Consequently, it is important for practitioners to create a space in which a parent feels able to express anything, knowing that they will not be judged for it. For many parents, this may be sufficient to enable them to express some of their unspoken thoughts. However indications from this study show that perhaps practitioners need to go one step further and explicitly name the fact that some parents in similar situations have thoughts and feelings of which they are ashamed, and such things are surprisingly common and understandable.

Practitioners should also explicitly name the competing demands of 'grief' and 'on-going parenting' and provide space for parents to acknowledge and explore the difficulties that creates, leading to ideas and strategies which may help parents manage these demands.

A space to share and 'normalise' these experiences may help create a 'less-self blaming' narrative and give parents some freedom from their guilt, whilst integrating the conflicting aspects of 'grief' and 'parenting'. It would also enable others to understand parental bereavement experiences more fully and help society better support them and their children.

Louise illustrates these ideas when she says:

> *"if at some point, if I'd have had some literature that would have told me at the time that other parents felt the same, that were in the same position, I think it would have helped me to feel less…like an alien. Um…you know, I think, I think it's necessary for people to… understand that, well I hope other people have felt almost the same, I'm sure they have…em..but I think it's important to be honest".*   *(Louise)*

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5.2.4 Bereavement theory and research in practise

This study has considered the wider societal discourses ('being a good parent', gender, 'how to grieve') that may contribute to the experience of parental bereavement. Illuminating these discourses may be helpful for parents; and a therapeutic approach which holds this as a central tenet is narrative therapy (White & Epston, 1990) Narrative therapy is an approach to "problems" which "involves opening space for the authoring of alternative stories, the possibility of which have previously been marginalized by the dominant oppressive narrative which maintains the problem" (Carr, 1998, p.485). This approach may be a useful method of working with bereaved parents.

However, illuminating societal discourses, such as those informed by bereavement theory and research (DPM (Stroebe & Schut, 1999); Crehan, (2004)) does not mean these have to be discarded; just understood as a product of discourse and culture. Practitioners must prioritise the unique make up of bereaved families and their stories; and "be far more curious about what those they are serving find comforting, sustaining, and enlivening. They should invite people more often into the role of making meaning of their own experience, rather than interpreting their experience for them to fit with theory' (Hedtke & Winslade, 2004, p.44).

5.2.5 Recognising the needs of children in the family

Some parents' told stories that illustrated their inability to attend to the needs of their children, especially emotionally. It is almost inevitable that the parents' grief will impact upon their ability to parent the surviving children. Many of the children of these parents struggled with troubles of their own.

This does not mean this experience has to be catastrophic for children, especially if some additional support can be provided to supplement their parents. When looking at the literature relating to young carers of parents with mental health difficulties, young people often indicate that they do not want a therapist at difficult times but would rather have a 'parental understudy' (e.g. grandparents, aunts and uncles, teachers etc.); research suggests that "the availability of one or more adults with whom the child can develop a supportive relationship is a key factor in a child's development of resilience" (Cooklin, 2009, p.18). This research also suggests that being able to make sense of parental difficulties is helpful (Cooklin, 2009), this would

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suggest that bereaved siblings may benefit from having time to make sense of their parent's grief and having it 'normalised', perhaps this work can be done with a 'parental understudy' with practitioners or alongside other bereaved siblings.

Ultimately, practitioners need to be mindful of the potential impact of parental bereavement on surviving siblings, and work hard not to become silenced by the dominant narrative of the parent's grief, and provide support for siblings.

5.3 Limitations and Methodological considerations

5.3.1 Strengths

A strength of this study is its consideration of the relational aspects of family bereavement, which is acknowledged as an under-researched area. Consequently, it contributes to our understanding of the death of a child in the family and how this influences the surviving emotional relationship between parents and children. This understanding is achieved through the use of a narrative approach which also allowed the voices of bereaved parents to be directly heard.

Additionally, using a narrative approach provided a consideration of the psychological and social methods of meaning making (Weatherhead, 2011), it has enabled space for alternative narratives which broaden understanding and may aid the development of better support and interventions for bereaved families, whilst helping parents not to feel so 'isolated' in their emotional experience.

5.3.2 Limitations

There are limitations of this study. Firstly, this study has been restricted by the word limit of this thesis, which has restricted an exploration of some aspects of the stories told by parents; for example, parent's relationship to help and professionally supplied therapy has not been considered, as although it was an interesting area it did not directly address the research question. However, as this study has used narrative methodology, it was never expected that it would comprehensively reflect the experience of bereaved parents.

Secondly, it could be argued that the sample used in this study is biased. All the parent's interviewed were White British, married at the time of bereavement and similar in age. Additionally, the sample were all recruited from a bereavement

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organisation which implies a particular relationship and openness to participate in research, a phenomena noted by Bonanno and Kaltman (2001), the majority had also engaged in some form of therapy prior to interview. The sample was also predominately made up of mothers, with only one interview with a father. These factors provide limitations in terms of ethnicity, cultural and gender. However, qualitative research generally has smaller sample sizes than quantitative studies which restrict their ability to provide a breath of demographic variability. Future research should attempt to capture more diverse populations in terms of cultural, ethnicity and gender.

Additionally, by focusing on the stories told by parents about the parent and child relationship, I did not access stories told by the children and was not able to observe the relationships within these families; this needs to be considered when interpreting the study's findings and also points to further research (see 5.3.3).

It is also important to recognise my own limitations as a researcher and how these may have influenced my construction of the narratives. Johnson and Clarke (2003) suggest that researchers with a clinical background may find their therapeutic skills in opposition to the requirements of a researcher. My therapeutic leaning towards 'formulating' clients, was certainly something I needed to be mindful of during the interview and analysis. In addition to my personal position as a 'bereaved sibling' and the 'emotional cost' of 'repetitive exposure to emotionally charged' material (Gilbert, 2010) which may have limited my effectiveness as a researcher. In an effort to limit the influence of these factors I kept as close to the 'text' as possible and used the guidance of supervision.

5.3.3. Suggestions for future research

A narrative inquiry uses small sample sizes to enable a collection of rich data and a detailed analysis (Wells, 2011). Consequently, further research could be completed with different and varied samples; this would build and broaden our understanding of parent-child emotional relationships after the death of a sibling. This additional research would hopefully help strengthen an alternative narrative from which parents and families can draw an understanding of their own bereavement experience.

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Further research could also focus on particular aspects of this study, for example, how getting 'stuck in the fog' influences relationships or further exploration of the protective factors in the emotional relationship.

This study seems to have illuminated the influence of the pre-bereavement story on parent-child relationships; I would suggest this is area that requires future research using both qualitative and quantitative methodology.   Perhaps most importantly, future research should attempt to capture the stories and voices of the bereaved siblings which have largely gone unheard in this study and in previous research. If these stories can be understood alongside parental narratives, a fuller understanding of family bereavement can be established.

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5.4 Final reflections

As I approach this final section, and what appears to the reader to be the end of my research story, I write with a sense of relief and trepidation. Relief, as this journey has felt long, emotionally exhausting and intellectually demanding even though filled with a sense of privilege and purpose. And trepidation, as I make public my very private journey, but most importantly reveal my co-construction of the very personal bereavement stories gifted to me by June, Clare, Louise, Mary and Andrew. I feel the heavy weight of wanting to have represented their stories with a resonance to those they felt they told. Narrative theorists talk of the impossibility of the task; but theory and practise, living and telling, and professional and personal are very different 'things'.

I hope I have been able to reveal my own position throughout, and have provided enough space for the reader to create their own constructions from the stories told. My final hope is this study in some small way can help bereaved parents and surviving siblings in the future, by helping them and the professionals who work with them, develop a deeper understanding of their differing perspectives.

I will end by completing the Christopher Robin quote which I used at the beginning of my personal position (section 1.2).

> *"If ever there is tomorrow when we're not together…there is something you must always remember, you are braver than you believe, stronger than you seem, and smarter than you think…..but the most important thing is, even if we're apart, I'll always be with you".*
>
> *Christopher Robin to Winnie the Pooh (AA Milne)*

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Appendices

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Appendix 1: Literature Review Strategy

Stage 1: Initial Search

At the start of the study a general exploratory review of relevant literature of the subject area was completed by:

- Reviewing relevant books with the Learning Resource Centre (LRC) at the University of Hertfordshire
- Searching on-line academic databases supplied by the LRC which included Google Scholar and Web of Science using parental bereavement and sibling loss as major search terms.

Stage 2: Follow-up on key references

At this stage any key references or articles that were identified in my initial search were followed up, and if necessary any appropriate articles/books were located.

Stage 3: Requests made to professionals working in the field.

While on placement at a family bereavement service, experts in child bereavement and trauma were asked to supply any relevant literature.

Stage 4: Detailed review of specific topic areas

At this point a more detailed review of the literature was completed. Details of parameters of the search are detailed below:

Inclusion criteria:

- Material written in English
- Peer reviewed journal articles
- Material that focused on parental and/or sibling bereavement

Exclusion criteria:

- Material that focused on other types of loss, including loss of a parent

Search Terms:

Databases were searched using the appropriate Boolean operators and a combination of search terms:

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- Parent - parent*, maternal, paternal, mother, father
- Sibling - sibling, brother*, sister*, child*
- Family – family, system*
- Parenting - parenting, child rearing, raising children
- Impact - impact, effect, outcome, influence
- Death - death, grie*, bereave*, loss
- Narrative – stor*, narrative, biography
- Qualitative method –narrative*, qualitative*, qualitative method, meaning making, review*, meta-analysis

Any material that could not be located at the LRC was requested on an inter-library loan from the British Library.

Databases used:

- Scopus
- Google Scholar
- Cochrane
- Annual Reviews
- Psyinfo

Lastly a general search of the internet using Google was completed, to review any relevant material that was available from bereavement organisations (for example Compassionate Friends, Winston's Wish etc.)

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Appendix 2: CBS Board Approval

12th March 2014

Dear Sarah,

Re: ███████████████████ research

As you know we are delighted to be a part of your research, and we are keen to support you in anyway that we can. If any of your participants would like to be interviewed here at ████████ you can of course use any available clinical rooms here to conduct your interviews. Please make sure that you book the room in the usual way and cancel the booking if it is not required. Please also re-acquaint yourself with our lone-worker policy and ensure that you do not put yourself at risk.

If you would like any more information or wish to discuss this matter further please do not hesitate to contact me.

Yours sincerely

MEMBER OF
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Appendix 3: University of Hertfordshire Ethical Approval

University of Hertfordshire UH

UNIVERSITY OF HERTFORDSHIRE
HEALTH & HUMAN SCIENCES

ETHICS APPROVAL NOTIFICATION

TO	Sarah Shankar
CC	Lizette Nolte
FROM	Dr R Southern, Health and Human Sciences ECDA Chairman
DATE	2 April 2014

Protocol number: **LMS/PG/UH/00185**

Title of study: Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.

Your application for ethical approval has been accepted and approved by the ECDA for your school.

This approval is valid:

From: 2 April 2014

To: 31 March 2015

Please note:

Approval applies specifically to the research study/methodology and timings as detailed in your Form EC1. Should you amend any aspect of your research, or wish to apply for an extension to your study, you will need your supervisor's approval and must complete and submit form EC2. In cases where the amendments to the original study are deemed to be substantial, a new Form EC1 may need to be completed prior to the study being undertaken.

Should adverse circumstances arise during this study such as physical reaction/harm, mental/emotional harm, intrusion of privacy or breach of confidentiality this must be reported to the approving Committee immediately. Failure to report adverse circumstance/s would be considered misconduct.

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.

Students must include this Approval Notification with their submission.

Appendix 4: Invite to participate

An invitation to help us with a new research project

Study Title: *Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.*

Dear name,

As you may know ███████ was originally created to meet the needs of children and their families following the death of someone close. One of the ways we feel we can help families is by supporting clinically relevant research.

As a family who have come to ███████ in the past following the death of your daughter/son, we wondered if you would like to join a research project focusing on bereaved parents' stories of their emotional relationship with their surviving children.

To help you decide if you would like to take part in the research project we have enclosed an information sheet which contains details about why the research is being done and what would be involved. We hope it will answer the majority of any questions you may have.

Please consider this information sheet carefully, as it is important you fully understand what would be involved. You may want to talk it through with your family, friends or even members of staff at ███████ After considering the information provided, and if you feel you would like to take part in the study, please contact me using the details outlined at the end of the information sheet.

Thank you for taking the time to read through this information.

Sarah Shankar
Clinical Psychologist in Training
University of Hertfordshire

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Appendix 5: Information Sheet for Participants

Information Sheet: Participation in Research (July 21014)

Study title: Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.

Main investigator: Sarah Shankar, Clinical Psychologist in Training at University of Hertfordshire.

Why are we doing this research?

The death of a child within a family is often a traumatic and life-changing event, with the pain and distress parents feel often described as incapacitating. Many parents find themselves having to manage their grief while also having to parent surviving children. Parents often find it takes longer than expected to recover a level of stability in their lives, even though the mourning process may be life-long. As a child who experienced the death of my sister and the grief of my parents, I understand the impact this can have on a family first hand, and the challenges that may be faced by surviving siblings.

Consequently, I am hoping that this research project will explore how bereaved parents experience their emotional relationships with surviving children over time, and lead us to a better understanding of how families and their relationships can be more effectively supported after the death of a child.

Part One: if you think you would like to take part? Please read on………

Why have I been invited to take part?

The study is focused on parents who have experienced the death of a child while also having surviving children to parent. The study is being supported by the *CBS*[7]. As you have lived through this experience and been supported by the *CBS* service in the past you have been invited to participate.

---

[7] Name of child bereavement service changed to maintain issues of confidentiality and anonymity

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Do I have to take part?

No. It is up to you. If you decide to take part, we will ask you for your consent (permission) by signing a consent form. We will give you a copy of this information sheet and your signed form to keep. You are free and able to withdraw from the study at any time without giving a reason. If you decide to stop, this will not affect your relationship with the *CBS* in any way.

What do I have to do?

If you decide to take part your main involvement in the study will be to participate in a conversation, sometimes called a research interview, with the main researcher (Sarah Shankar). This one to one interview will take approximately an hour and will be audio-recorded.

What will happen to me if I take part?

If you decide to take part, please contact me and let me know that you are interested in participating and the process will be as follows:

- I will contact you by phone or email to arrange a time to meet at your convenience.
    - We can meet either at your home or at *CBS*, dependent on what is easier for you. If you do want to meet at *CBS* we can give you the money for your travel.
    - If both parents choose to take part, the interviews will be completed separately.
    - We will need to ensure that the location has a private and quiet space and we have at least an hour and a half of uninterrupted time.
- When we meet for the research interview we will begin by discussing and obtaining your written and informed consent to participate.
- We will then have a conversation about your experiences. I will ask some questions about your relationship with your surviving children. I will use a digital voice recorder so that I can record everything we've talked about and use it in my research.
- This conversation will probably last about an hour, but this will depend on how much you feel you want to share. We can take a break if you feel it would be helpful.

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- We only need to meet once.
- As the focus of the conversation will be on the influence of a distressing experience in your life, it is likely you may feel emotional at times. There will be the opportunity to talk to myself after our meeting if you'd like to.
- After our conversation, there will be a period of time when I will be writing up the study. If you would like to know the results or give feedback, we can determine the most convenient way of doing that.

Is what I say private?

Our conversation will be private. The recorded interview will be transcribed into a written document. Only the main researcher will be able to match you with your written interview. Your transcribed written interview will be used as data for the study. The research supervisors (█████████████████████) and examiners will therefore have access to an anonymized transcript of our discussion, and in case of publication, a wider audience will read direct anonymized quotations from our interview, alongside quotations from others who participate in the research. Every effort will be made to ensure that you and your family can not be identified from the text.

The only time we would need to break confidentiality is if something that made me worry about your safety or the safety of someone else, in which that case I may have to share that information with others.

Is there anything to be worried about if I take part?

As previously discussed, there is the possibility that you may feel upset during or after our conversation. This is very normal. You can always let me know if you would rather not answer a question, or would rather move on to the next. After the interview, if you feel you would like to talk through anything the interview may have bought up for you someone at *CBS* will be available. However, the aim of this study is not to be upsetting.

What are the possible benefits of taking part?

Lots of people find talking about their experiences helpful, and sometimes find it useful to have an opportunity to reflect on their experience. We cannot promise the study will help you but the information we get might help inform the support provided

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to other families whose have experienced the death of a child in the family in the future.

We hope that has answered the main questions you may have.

If you are still interested, please continue, if not thank you for reading so far…….

Part Two: if you STILL think you would like to take part? Please read on………

What happens when the research is finished?

Using the data from our conversation

As already briefly described, our interview will be typed up, this may be by myself or a transcriber, but they will only listen to the interview, they will have no personal information and they will sign a confidentiality agreement. Your identity will be kept completely private by changing your name and any other information that could identify who you are (like friends or members of your family's names). You can leave the study at any time before our conversation is typed.

Once I've completed the work with our conversation, the thesis has been marked and any publications have been made, I will destroy the recording I made. I will keep the typed up conversations, with the names changed for 3 years in case I need them again but I'll lock them away.

Ongoing support
- I will be available when we have finished the interview to talk and reflect on our conversation and your immediate thoughts and feelings.
- A member of staff at *CBS* will be available to talk with you if you feel you would like to speak to someone. Please contact the head of the bereavement service [8] at *CBS* if you would like to talk to someone in the team.

---

[8] Names changed to maintain confidentiality and anonymity

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- You may not feel you need any more support and may feel you don't want to speak to anyone else, that's totally fine too.

Who has reviewed the study?

Before any research goes ahead, any proposed studies need to be checked by a Research Ethics Committee. They make sure that any research is ethically sound. This study has been checked by the *CBS* clinical team, the *CBS* Board and the University of Hertfordshire Research Ethics Committee.

What if I have a complaint about the study?[9]

If you have a complaint about the study you can contact either or both of the research supervisors:

██

University of Hertfordshire, Faculty of Health & Human Sciences.

Email: ███████████   Telephone: 01707 █████

███████████████████████████████████████

Email: ███████████████   Telephone: +44 (0)20 ████████

What do I do if I would like to participate? Please contact me by:

By Post: Please complete the slip below and post using the stamped addressed envelope provided to: CBS – RESEARCH PROJECT

      C/O █████████████████

      Child Bereavement Service,

By telephone: 01███ █████

By Email: ████████████.ac.uk

---

[9] Some details have been changed to maintain confidentiality and anonymity

Alternatively:

If you have any questions please send me an email at ▮▮▮▮▮▮▮▮▮▮ac.uk. If you leave your details and I will email or call you back, if you felt it would be helpful I would be happy to meet face-to-face to discuss any concerns.

Study title: Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.

Name :_____and

_____

I/we would like to participate in the above study and would be happy for you to contact me via:

Email_____ /

_____

Phone:_____/

_____

Signature/s:_____/_____

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Appendix 6: Consent form

CONSENT FORM

Study Title: Bereaved parents stories of their emotional relationship with their surviving children following the death of another.

Researcher: Sarah Shankar

Please read the following statements carefully:

1 I confirm that I have read and understood the information sheet for participants (July 2014) for the above study. I have had the opportunity to think about the information, ask any questions and have these questions answered satisfactorily.

2 I have been given the names and contact details of key people involved in the study.

3 I have been given details about my involvement in the study including the possible risks and potential benefits of participating. I am am aware that my participation is voluntary and I can withdraw from the study at any time, without disadvantage or having to give a reason.

4 I have been given information about the possibility of my suffering distress. I have been told about the support that will be offered to me in the event of this happening and I have been assured that this will be provided at no cost to myself.

5 I have been told how the information I provided about myself and my family will be managed i.e. how it will be kept, who will have access to it and how it will or may be used.

6 It has been explained to me what will happen once the research study is completed.

On reading the statements above and I freely agree to take part in the study

Name of
Participant……………………………………………………………………………………………

Participant
Address ……………………………………………………………………………………………….

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

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

University of Hertfordshire UH

Bereaved parents stories of their emotional relationship with their surviving children following the death of another.

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Appendix 7: Demographic Form

DEMOGRAPHIC FORM

Study Title: Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.

Researcher: Sarah Shankar

Name			
DOB/Age			
Gender	Male / Female	Marriage Status	
Ethnicity			
Contact Details Address			
Phone Numbers Home Mobile			
Email Address			
GP Details			
Children	Name:		DOB:
	Name:		DOB:
	Name:		DOB:
	Name:		DOB:
Date of Bereavement			
Other services supporting			

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Appendix 8: Interview Schedule - Guidelines for Semi Structured Interview

<u>Title</u>: **Bereaved parents' stories of their emotional relationship with their surviving children following the death of another.**

Before the interview begins there will be:
- Introductions
- Ensure interview location is private and quiet. Explain the interview should take approximately 60-90 minutes.
- Check that information sheet has been read and understood. Provide an opportunity for participants to ask questions.
- Tell the participant if they are uncomfortable answering any questions, they are free to let the researcher know, and they do not need to answer.
- Tell the participant they should let the researcher know whenever s/he would like a break, or if s/he has had enough for that day; or no longer wants to continue.
- Explain there are no right or wrong answers.
- Review or signing of consent forms.

TURN ON RECORDER

Before recording starts the interviewer will:
- Recording of basic demographic information: age, contact details, ethnicity.
- Confirm the name of the child that has died and confirm the year of death.
- Check the participants understanding of the term 'emotional relationships. What do you understand to be the meaning of the term 'emotional relationship'? For example, not the practical day-to-day things we do for our children which show them we care but how we connect to them through our feelings and emotions.

1a. Optional Introductory Question(s) - *dependent on rapport built and information gained during administration of forms.*
Before we get started I was just wondering if you could tell me a bit about your life today, and who lives with you in your home at the moment?
Prompts:　　Names
　　　　　　Ages
　　　　　　Gender
　　　　　　Relationship status
　　　　　　Occupations

Who else in your family are you close to/or is important in your life?

1b. Introduction – loss story

As you know the **focus of this interview** is on your **emotional relationship with your surviving child(ren)** but before we get into the main part of the interview, I was **wondering if you would like to tell me about _____ and how (he/she) died?**

2. Emotional relationship with surviving child

Acknowledge story and transition into main part of interview……

So I was wondering, **with the story you have shared so far as a context for the main focus of the interview**, which is your emotional relationship with your surviving child(ren), I was wondering if you could **tell me what your emotional relationship with _____ was like generally like before the death/illness** of _____?

Prompt:
How close did you feel to _____?
How do you demonstrate that?
What do remember most about your emotional relationship at that time?
What would your partner say about your emotional relationship with _____at that time?
When did you notice times of emotional closeness? What created the / influenced them? (People, places events)?
When did you notice times of emotional detachment? What created the / influenced them? (People, places events)

At the time of the loss
I am wondering **how you felt your emotional relationship with _____ was at the time of _____ death?**

Prompt:
How was that relationship different?
How was it better? How was it worse?
How did you demonstrate that to them?
What do remember most about your emotional relationship at that time?
What would your partner say about your emotional relationship with _____at that time?

When did you notice times of emotional closeness? What created the / influenced them? (People, places events)?
When did you notice times of emotional detachment? What created the / influenced them? (People, places events)

After
I am wondering what has happened to your emotional relationship since the death of _____?

Prompt:
How is that relationship different?
Is it better? Is it worse?
How do you demonstrate that to them?
What would your partner say about your emotional relationship with _____ since?
When did you notice times of emotional closeness? What created the / influenced them? (People, places events)?
When did you notice times of emotional detachment? What created the / influenced them? (People, places events)

3. Surviving children's stories

If _____ was here with us now, I am wondering what you imagine they might be saying about their emotional relationship with you?

Prompts:
Before
During
After
Now

> Say and be quiet……repeat if needed, leave space and LISTEN

Would you mind if I look at my interview schedule and see if there is anything I've missed?
Can reflect on a particular point, ask for more information….

NB: If more than one child, ask a general question and then ask about each child separately.

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AFTER THE INTERVIEW

- **Feedback**
    - o **Your experience of interview**
    - o **I was wondering if the interview, had made you think about things you haven't thought about before…..?**
- **Can I call contact you in a week or so…..**
- **If any difficulties ……remind them of support available, ask how they would manage difficult feelings**
- **Write straight after interview, reflective diary**

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Appendix 9: Transcription Agreement

Transcription Agreement

Doctorate in Clinical Psychology
University of Hertfordshire

Transcription confidentiality/ non-disclosure agreement
Researcher: Sarah Shankar

This non-disclosure agreement is in reference to the following parties:

Sarah Shankar

And

Alltypes-secretarial.co.uk (Lesley Beadsley)

The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.

The recipient agrees to store all information in a safe and secure way.

The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.

The recipient agrees to return and or destroy any copies of the recordings they were able to access provided by the discloser.

Signed:.....

Name:.... LESLEY BEADSLEY

Date:.... 5/9/14

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1.

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Appendix 10: Transcription Convention (Poland, 2002, 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-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.

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Appendix 11: Summary of Elliot et al.'s (1999) Evolving Guidelines for Qualitative Research

Table 1. Evolving Guidelines for Publication of Qualitative Research Studies in Psychology and Related Fields

---

A. Publishability Guidelines Shared by Both Qualitative and Quantitative Approaches
1. Explicit scientific context and purpose
2. Appropriate methods
3. Respect for participants
4. Specification of methods
5. Appropriate discussion
6. Clarity of presentation
7. Contribution to knowledge

B. Publishability Guidelines Especially Pertinent to Qualitative Research
1. Owning one's perspective
2. Situating the sample
3. Grounding in examples
4. Providing credibility checks
5. Coherence
6. Accomplishing general vs. specific research tasks
7. Resonating with readers

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Appendix 12: Examples of reflective process

No3:

felt quite unsettled after this interview
maybe due to the amazing surroundings
& no3's apparent confidence, or that
i was in her home. I felt there of a
I felt there was a connection but
this connection was turned off
very quickly at the end & she said
'that's done'.
I felt she was very honest, open &
she only became emotional towards
the end when thinking about the
experience of providing a sibling

↳ I feel unsettled . . . . .
wonder ▬▬▬▬▬▬ has
concerned seemed me?

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(Mary)

Reflexive read *

22 - wonder if that was a thought for my parents.
28 - quite a modern western way of thinking, nor
    what my parents experience would have been.
41 - I'm near her age & I wanted a second child
62 - I was 4 - was that how I felt?
115 - I have an only child & triggers my own anxietys
253 - did mum feel that about me.
265 - replacement child?
277 - my daughter sleeps with me.
291 - does ruby?
311 - how I feel about my daughter
335 - ██████████? why I'm doing this study
372 - reminds me of my doctor visits when
    I was at middle school.
378 - ████████████████████████████
420 - thin █████████ feel that about me
    when an████████████
436 ⁴⁴⁰ — in
461 - has my mum ever felt that
469 - my mom's experience?
475-6 - ‿ a
478-484 — this is depression but feels the
    same as grief
497 - perhaps to helped develop that
    reflexive position from my childposition.
583-4 ██████ w experience.
592 - ‿ in
610 - m█████e (my experience)
624 - I wonder if mum felt like that
█████████████████████████████████
    illness.

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Appendix 13: Examples of working transcripts

disconnected

→ control

- compensate

1178 disconnected with Alice as well. I sp- I wasn't able to stop it happening I, I wasn't
1179 aware of it, I don't think even.
1180 I: Umm
1181 L: But um I've managed to (pause) errr....not compensate for that but I've managed
1182 to get back on track with Alice, but I haven't with Toby.
1183 I: Okay
1184 L: So at that time, I've written down and I've underlined it....that I was disconnected,
1185 distant, was distant from not just- not just Toby and Alice but everyone. I was totally
1186 preoccupied....with Jack and (starts to cry) and I was distressed you know I
1187 really....cried a lot (sniffs) I think I just switched off from them. I've put here I wasn't
1188 aware of Toby and Alice (pause) and um (sniffs) and Richard took over
1189 everything...at that time he did...you know, he was- he did the shop- I didn't shop for
1190 a long time. He did the cooking, the cleaning, the shopping and worked. And all I did
1191 was....obsess about Jack. I don't even know how I filled my days. I was working, I'd
1192 gone back to work by then but erm (sniffs) just everything was about Jack (pause)
1193 remembering him. Erm...I'd find projects I would just find something else to do that
1194 was about Jack. Ummm....and I just left them to get on with it. And I think um....I
1195 think I was lucky (sniffs) that I was able to do that and that was at the time that I saw
1196 the...ladies at Child and Family Services
1197 I: Yeah
1198 L: you know, and at one, every week I was going for one, either one lady or the
1199 other...erm...and I was very lucky that Richard just took over my role really...for I
1200 would say....I don't know how long...but definitely six months, maybe even a year.
1201 But I'd have days when I would be better (pause) and the it would sort of gradually I
1202 got better over time but (pause) um...at that time I think I disconnected from Toby
1203 and Alice as well.
1204 I: Yeah
1205 L: But I've been able to..luckily, because of her age and maybe because of her
1206 gender I don't know, I've been able to (pause) re- you know erm...reconnect with
1207 her.
1208 I: So when you say kind of dissociate...what does- in your relationship with them,
1209 what did that kind of look like?
1210 L: Um....well if I'm totally honest with you...which I will be and it's difficult to admit
1211 but (pause) (begins to cry) (sniff) I didn't- I didn't even want to be around them. I
1212 didn't want- (pause) if I heard-...if I heard them coming into the room I would get up
1213 and go...somewhere else where I could be alone, just with my thoughts (sniff)
1214 so....Alice was very chatty...you know, young girl then and little girls talk a lot and I
1215 would- it would grate on me her voice even...and I used to be- I used to think shut
1216 up, will you just shut up talking (sniff) and Toby would come and ask (long pause) for
1217 something simple like I don't know....just you know, things that kids ask for...where
1218 his socks were or something and I would be- I would feel anger towards him,
1219 because he needed me and it was, it was all erm (long pause) I felt as though (long
1220 pause) I felt annoyed by their need for me, like if they needed dinner I'd think oh God
1221 I've got to cook, I've got to cook, and if it was only me, if it was just me I wouldn't
1222 bother cooking, I wouldn't you know, why have I got to cook.
1223 I: Hmm
1224 L: I can't you know, and they- Alice was only little, you know and Toby was probably
1225 ████████ then he probably could have fended for himself, but erm (pause) it was-
1226 it's a terrible thing to admit that, but I'm just being honest. I can remember times
1227 walking out of the room (pause) I couldn't bear the sound of her voice (sniffs) but
1228 (pause) and I think Toby- recently Toby said to me..he only said it once but I'm sure
1229 that's how he feels. He said maybe you'd have preferred it if it had been me (sniffs)

grief / distress

obsess about Jack

deny of disconnection

→ mother hood role

age.

gender

→ reconnection

disconnect physical

cycle of physical disconnection

→ need.

sickness of disconnection

voice

rejection / disconnection / insecurity

24

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[handwritten: trauma!!]

205 picked him up and soothed him he just wanted to get back in his cot. So Andrew put
206 him back in his cot (pause) um and then....obviously got the steamer going. And
207 anyway the next morning Andrew, always before work, would get up, go and get the
208 milk and a cup of tea for me, plonk it by me so the milk and my cup of tea and he
209 walked upstairs and I just heard him scream (pause) shouting no. And um he'd
210 stopped- he'd died, his, his basically, his tubes had closed up. So he'd he'd
211 suffocated, he'd died, so he just looked asleep apart from a tiny little of bit of blood
212 out of his mouth which is quite normal I think. Tiny...he just looked fast asleep and

[handwritten: like sleeping beauty]

213 ██
214 ██
215 ██
216 ██

[handwritten: guilt could I have changed anything]

217 everybody, um I didn't really want to go, I did go and my one question, my only one
218 question was um (pause) well it was two, did he suffer, no. If I'd brought him in at
219 one o'clock in the morning would he be here now? That's my only question.
220 And....the main doctor she said if I'd have been on duty that night I probably would
221 have sent you home. She said because unless there are blood tests or had he have
222 been very severe at that point, it would have been too late, so he might not have be
223 the child that you brought in, to take home again. So I'd probably would have sent
224 you home if I'd have been on duty. So it's one of those very very, it's like a silent
225 killer.

[handwritten: uncontrollable came from nowhere guilt]

226 I: Umm
227 M: So...and Emma was away. What, what was so awful about- well awful and not
228 awful in two different ways. It ██████████████████████████████████
229 to a restaurant. And um...And ██████████████████████████████████

[handwritten: Emma at grandparents]

230 on great form, we had such a lovely family day with Andrew's parents and
231 everybody. And we left Emma there for a few days, to stay with Grandma, cos
232 they've got a VERY close relationship. INCREDIBLY close and so we left Emma
233 there, came home..and...he died on the Monday (pause) Monday night, or Monday
234 morning sorry, Monday morning, yeah we found him Monday morning. And Emma
235 wasn't there....so a lot of Emma from the very beginning struggled with that she
236 wished she'd been there, she felt it was her, had she had been there he might not
237 have died.

[handwritten: guilt "could have done something"]

238 I: Mmm.
239 M: But the flip side of that is, as Andrew said, her bed was next to his and she'd
240 quite often go in the morning and get him.
241 I: Yeah.
242 M: So you know, if she'd have found him, she, I mean it would have been, you
243 know. Andrew believes in his HEART that he was the right person to find Paul. He,
244 he believes that totally. So you know Emma's, real for her was, if she had been
245 here, would he still be here and that was really difficult.

[handwritten: Andrew - right person Emma - could have changed it]

246 I: Ummm
247 M: And um going to the grave with her was terrible. I mean you know oh...her and I
248 were just, oh it was a nightmare. I didn't want to go. She wanted to go. So I'd take
249 her. She'd then have a complete melt down, I literally- she'd run away, hide, oh it
250 was awful. It was awful. And I think you know all those things you realise I just
251 needed help

[handwritten: needed help.]

252 I: yeah
253 M: with her because I couldn't cope. I couldn't cope with her. I found it very, very
254 difficult.
255 I: So before Daniel came along, what was your relationship-
256 M: Paul.

[handwritten: fairytale to a nightmare / silent killer]

[handwritten: coping.]

5

Bereaved parents stories of their emotional relationship with their surviving children following the death of another.

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Clare

<u>Structure</u>

(1)

traumatic

<u>a story with little emotion</u>

- 138-140 'not very nice'
- 152-157 'un sort of tangled'
- 159-165 'then um she died'
- 167-169 we had to let her go
- 179-180 couldn't have sa-
- 184-191 there was nothing else i could do.
- 209-211 newspapers.
- 218-219 want to print in paper.
- 221-226 child & chinese whispers.
- 231-235 she'd get the cord
- 541-544 told by a child
- 598 he is my baby now.

602: i don't think it
changed anything
652 cry, this that
& the other.
657 you can't
sit there...

674-690.
little emotion/
factual recount.

692-700 first couple
of weeks.

<u>a story that needed lots of direction from interviewer.</u>

278-285 prompts from interviewer.
354-360 closer to lucy... umm.
395-404 more time together...
43-421 hard to remember.
596-610 lots of questions from interviewer.
625-628 -"-
671-673. now you were?

102—
119
lots for
death
story/
Jessica.

Bereaved parents stories of their emotional relationship with their surviving children following the death of another.

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