

**“Everything about being a parent when you’ve lost is bittersweet”. Couples’
experiences of parenting a pre-adolescent child following perinatal loss.**

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A thesis submitted for the Doctorate in Clinical Psychology

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April 2024

Acknowledgements

I would like to thank the couples who gave their time to participate in this research and generously shared their stories with me. Without these couples, the research would not have been possible.

I would like to thank my supervisors, John and Richard, for always making time to meet and always being supportive and encouraging. Thank you to Ben at Sands for helping me to keep the parents and families for whom I am doing this research at the forefront.

Finally, thank you to my parents and my sister, for your love and support, always. This research is for Charlotte.

“When you lose someone you love, they never really leave you. They move into a special place in your heart.”

– Mrs. Frankenstein, Frankenweenie, Walt Disney Pictures 2012

Abstract

Background: Perinatal loss is defined as loss at any stage of pregnancy, up to the first 30 days of life. Perinatal loss occurs in one in four pregnancies and can be a traumatic life experience for parents. It is known that subsequent pregnancies are characterised by increased anxiety and depression, however, very little is known about the impact of perinatal loss beyond the birth of subsequent children.

Aims: This research aims to consider the impact of perinatal loss on subsequent parenting through the experiences and perspectives of both parents. The study intends to explore how couples raise a child in the context of prior perinatal loss and to situate fathers and partners within the narrative of perinatal loss research.

Methodology: Fifteen couples who had lost a baby or babies and gone on to have a subsequent child participated in semi-structured interviews in which they shared their stories with the researcher. These stories were then transcribed and analysed using narrative analysis.

Results: The research identified narrative features including ‘the chapter stays open’ and ‘gendered discourses’ and narrative types including ‘stories of risk consciousness’ and ‘stories of gratitude’.

Discussion: Parents continued to develop their relationship with their children who had died and they remained a part of their family narrative. Parents sometimes shared differing public and personal stories of parenting in the context of prior perinatal loss that appeared to be influenced by gender and wider societal discourses. The couple’s experiences of baby loss increased risk consciousness and also gratitude when parenting subsequent children. The ways in which baby loss influenced parents’ narratives were not mutually exclusive. These narratives interlinked and parents moved between different narrative types

at different times in the process of adjusting to subsequent parenthood. Directions for further research and the clinical implications of the current research are discussed.

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1 Introduction Chapter

1.1 Chapter Overview

To introduce the study, this chapter begins by outlining relevant research regarding grief and bereavement, and then more specifically considers this in the context of perinatal loss. Different theoretical models of grief are then presented.

A systematic review of the literature is presented to consider what is known about the impact of baby loss on both mothers and fathers. This review is concluded by presenting a new line of argument from the existing literature. This is then discussed in the context of the wider literature and clinical practice. The chapter concludes by outlining the aims and objectives of the current research study.

1.2 Background

1.2.1 Bereavement and Grief

The loss of a loved one is a normal and universal human experience. A population-based Canadian study revealed that 96% of adults have grieved the death of a loved one (Wilson et al., 2016). According to Krull (2023), approximately 2.5 million people die in the United States annually, each leaving behind an average of 5 people grieving. Bereavement has been defined as the situation of having recently lost a significant person by death (Stroebe et al, 2001). Grief is then described as the emotional reaction to this situation (Stroebe et al, 2001). It is widely recognised in research that bereavement can have a negative and sometimes prolonged impact on people's lives (Prigerson et al., 2009; Stroebe, Schutt & Stroebe, 2007). Bereavement and grief are associated with an increased risk of physical illnesses such as insomnia, increased blood pressure and gastrointestinal issues and psychological consequences, such as depression, anxiety, and loneliness (Carr et al., 2001; de

Groot & Kollen, 2013; Monk et al., 2008; Parkes & Prigerson, 2013; Stroebe et al., 2007).

The time taken to adjust to bereavement or recover from grief can vary depending on many factors, including circumstances of death and cultural factors (Bonanno et al., 2008).

Generally, two years is considered the timeframe for recovery from grief (Zhang et al., 2006).

However, some people experience intense grief, that can be prolonged or even permanent (Byrne & Raphael, 1994; He et al., 2014; Middleton et al., 1996; Zhang et al., 2006). The loss of a close relationship by bereavement, such as that of a spouse, parent or child is associated with greater risks to health and more intense grief reactions (Thomas et al, 2014).

One of the most intense and overwhelming experiences of grief has been recognised to be when a parent loses a child (Rando, 1986; Rees, 2001). This type of loss is considered to go against the natural order of life as it is generally assumed that parents will die before their children. Parental bereavement impacts not only the parents as individuals but also the parent dyad, the family system and wider society (Rando 1986; Riches & Dawson, 2000).

1.2.2 Perinatal Loss

Perinatal loss is defined as the loss of a baby by miscarriage, early loss under 24 weeks of gestation, stillbirth beyond 24 weeks of gestation, or neonatal loss within the first 28 days of life (Fenstermacher & Hupcey, 2013; Charrois et al., 2020). According to the Office for National Statistics (ONS), there were 2,638 stillbirths in the UK in 2020, 1,719 neonatal deaths in England and Wales in 2020 and it is estimated that there are 250,000 miscarriages in the UK annually (ONS, 2021; ONS 2021). One in four pregnancies end in perinatal loss (Armstrong, 2004).

Perinatal loss can be a traumatic life event which can have long-lasting and severe psychological effects on expectant parents and their families. It is associated with depression,

anxiety, post-traumatic stress and sleeping problems (Boyle et al., 1996; Hughes & Riches, 2003).

Societal discourse tends to assume that perinatal loss carries a greater impact when it occurs at later stages of pregnancy. However, research shows detrimental impacts following perinatal loss at any stage. Women have been found to experience post-traumatic stress after a miscarriage, stillbirth, or neonatal death (Englehard et al., 2001; Jind, 2003; Turton et al., 2001). Research has also seen increased rates of suicide in women following perinatal loss of all types (Gissler et al., 1996; Klier et al., 2002). Perinatal loss can therefore be a significant, traumatic life event, regardless of the stage at which the loss occurred.

The perinatal loss literature to date largely focuses on mothers, and this is reflected in the healthcare system as care is primarily aimed at supporting mothers. Hospitals often have maternity wards, suggesting the focus, perinatally, is on mothers, rather than partners or fathers. Of the limited research exploring the impact of perinatal loss on fathers, much of the research found that fathers tend to suppress their feelings of grief (Murphy, 1998; Kohn & Moffitt, 1992). However, despite this repression of emotion, research has found that fathers can and do experience intense grief reactions following perinatal loss (Puddifoot & Johnson, 1999; Conway & Russell, 2000). This suppression of emotions may contribute to the societal discourse that fathers are less affected and therefore need less support, as their grief is often unwitnessed.

1.2.3 Theories of Grief

Having considered the impact of bereavement, it is also important to draw on theoretical models of grief to consider the process of grieving. Though it has been suggested that some theoretical models of grief do not adequately convey the experience of parental bereavement (Davies, 2004). Freud pioneered thinking around grief, suggesting that grief could be resolved by detaching oneself from the deceased (Freud, 1917). However, he later

challenged this line of thought after losing his own daughter and went on to write about grief as a more permanent state (Freud, 1917). Parkes (1972) then built on Bowlby's (1961) theory of attachment to develop four phases of grief. The phases included shock and numbness, yearning and searching, disorganisation and despair, and finally reorganisation and recovery. Kubler-Ross (1975) went on to propose a five-stage model of grief which outlined stages of denial, anger, bargaining, depression and acceptance. Kubler-Ross recognised that grief is not always a linear process and that there is no correct or assumed timescale for moving through this process. Worden (1982) later devised a task-focused model of grief which suggested four tasks of mourning. The first task being to gain acceptance of the reality of the death, then learning to live with the pain, thirdly to adjust to a world without the deceased and finally, to let go of emotional investment in the deceased and refocus on investing in ongoing relationships.

These traditional models of grief largely focus on a process of detaching from the deceased and eventually 'recovering' or working through grief. These were the dominant models of the last century. However, they soon came under criticism, with some suggesting they reflected a modernist, Westernised view of individualism, not allowing for the notion of interdependence (Silverman & Klass, 1996). Wortman and Silver (1989) reviewed the bereavement literature and challenged the assumptions and evidence base underpinning these traditional models. They suggested that further work was to be done to acknowledge the variability in the grief process. Rando (1986) also critiqued these models in relation to parental bereavement as he suggested that children are a physical representation of their parent and are therefore irreplaceable in comparison to other relationships. Rando went on to suggest that traditional models pathologized normal reactions to parental bereavement and these needed revision (Rando, 1991).

Myerhoff (1982) suggested that processing grief may include maintaining what has been lost by incorporating what is lost into the present, she suggested that remembering and keeping these memories may be vital to moving forward. Similarly, through his work in narrative therapy, Michael White (1988) introduced the idea of 'Saying hello again' as a new way for people to view grief. He noted that clients whom he was working therapeutically with through grief work were often unable to grieve according to traditional models. They felt unable to fully detach from and say 'goodbye' to their loved ones. He found that allowing clients to re-establish their relationships with their lost loved ones led to much more positive outcomes. Clients became more able to move forward with their grief. Michael White made his position clear that every experience of grief is unique and he does not discard the need to let go of and accept some parts of loss. However, he feels there may also be an additional process required in establishing a new relationship with the lost loved one and incorporating this new relationship into the bereaved person's life. Michael White wrote that this way of working was also applicable to parents who had lost young children, including perinatal loss. In line with these therapeutic discoveries, newer theories of grief have discarded the notion of detaching from or ending the emotional connection to the deceased. Instead, this connection became central to the process of grief.

The importance of maintaining a connection to the deceased was strongly reflected by Davies' (2004) model of continuing bonds. Continuing bonds posits a process of adjusting to the reality of the loss of a loved one, whilst maintaining a connection to them. Klass (1993) conducted a ten-year-long ethnographic study which found that parents maintained bonds with their deceased children and this provided them with solace. Further qualitative research has also supported the theory of continuing bonds (Rosenblatt, 2000; Talbot, 2002; Riches & Dawson, 1996).

One longitudinal study looking at bereaved individuals' ongoing attachment to the deceased found that those who reported more expressions of continuing bonds five years after the death of a loved one also reported high levels of distress and grief symptoms (Field et al., 2003). This suggests that continuing bonds may not always be a helpful process during bereavement. Stroebe and Schut (2005) reviewed the literature on continuing bonds and challenged whether this is an essential part of the grief process or more a complex part of it. They suggested that further research should be conducted to consider who may benefit from continuing bonds and who may find this unhelpful.

Further work began to recognise the variation in grief responses. Tonkin (1996) suggested that grief is not something that goes away or that people recover from, but rather something that individuals grow around and adjust to. This is reflective of a movement in the grief literature towards looking at how people cope with and adapt to grief, rather than detach or recover from it.

Stroebe and Schut (1999) developed the dual process model of grieving in direct response to their criticism of earlier frameworks. The dual process model gained traction and became one of the main models of grief. They suggested that a healthy grief process involves engaging in a dynamic process of oscillating between loss-oriented and restoration-oriented coping. The loss-oriented coping refers to grief work, whilst restoration-oriented coping refers to rebuilding. A development from more traditional models that suggested the only way to cope with grief was by facing this directly, whereas Stroebe and Schut felt that avoidance of the loss at times was not only normal but also a healthy part of the grief process. One study looking at parental bereavement following the death of a child by cancer found parental differences in grieving over time (Alam et al., 2012). They found that fathers used more restoration-oriented coping, whilst mothers engaged in more loss-oriented coping.

Due to the disenfranchised nature of perinatal loss, until recently, there has been a gap in understanding the impact of this form of loss on parents. However, as the loss of a child is considered to be one of the most significant forms of bereavement, it feels important to know more about how parents are impacted. Due to the paucity of literature considering both parents' experiences of perinatal loss, I will include infant bereavement in my exploration of parental grief. Knowing more about parents' grief processes may help to shape future research and tailor support to parent's needs. Given that differences have been found between mothers and fathers, it seems pertinent to include both experiences in the research. To address this, a systematic review of the literature exploring the impact of perinatal and infant bereavement on both mothers and fathers will be conducted.

1.3 Systematic Literature Review

In order to identify what is already known about the impact of baby loss on both mothers and fathers, a systematic review of the qualitative literature was conducted. This review aimed to synthesise the existing literature looking at the impact of baby loss on both parents. The search terms shown in Table 1 yielded 6,236 published papers.

1.3.1 Method

There is increasing acknowledgement that qualitative research contributes to knowledge and informs practice and policy development (Grant & Booth, 2009). Qualitative data often provides a richer, more in-depth understanding of the subject matter and is particularly useful in better understanding human experience. Therefore, qualitative syntheses are now recognised as an important tool to integrate data from different studies in order to better understand participant's experiences and perspectives (Lachal et al., 2017). Meta-synthesis is particularly useful for identifying gaps in research and thus in developing further

studies to address these gaps. Various methods for synthesising qualitative data have emerged and it is therefore important to select the most appropriate method for the given situation (Barbour & Barbour, 2003; Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2005).

To analyse and interpret research findings to date, a meta-ethnography was used to draw together concepts from across relevant studies for an original and richer interpretation of the research area. A meta-ethnography allows the researcher to create a more in-depth analysis by creating higher order themes through synthesis (Noblit & Hare, 1988; Sattar et al., 2021). Within meta-ethnography, Noblit and Hare suggest three ways of bringing together data. One process is referred to as '*reciprocal translational analysis*', where concepts from different studies are translated into one another, allowing overarching concepts to evolve. Another is '*refutational synthesis*' which allows the researcher to consider differences between studies. Finally, '*Line-of-argument synthesis*' involves bringing together the literature to form a whole greater than the sum of its parts, including the contexts from which the literature has emerged. Noblit and Hare (1988) suggest conducting seven phases, which this meta-ethnography has followed. These are getting started, deciding what is relevant, reading the relevant studies, seeing how these are related, translating the studies, synthesising translations, and expressing the synthesis.

Other methods for synthesising data were considered, including textual narrative synthesis and thematic synthesis. Textual narrative synthesis can be useful in showing heterogeneity between studies and comments on the context and characteristics of studies whilst examining the quality of each (Lucas et al., 2007). Thematic synthesis, on the other hand, may be most helpful for generating theory. Similar to Braun and Clarke's (2012) thematic analysis, thematic synthesis leans towards homogeneity as it groups data based on common themes (Barnett-Page & Thomas, 2009; Thomas & Harden, 2008). Thomas and Harden (2008) give three steps for conducting a thematic synthesis. The stages involve

coding the text, developing 'descriptive' themes and then 'analytic' themes. This process allows flexibility, drawing on a realist approach but allows the researcher to go beyond the primary data and offer a nuanced interpretation of the data (Thomas & Harden, 2008). Due to the lack of literature exploring both mothers' and fathers' experiences of perinatal loss, the studies included vary in their focus and it may therefore be helpful to identify commonalities across the data, rather than differences. Though it is necessary to consider the quality of the research, the paucity of literature means this should not be the focus of the current synthesis. Considering the different approaches in the context of the paucity of relevant data included in the literature, a meta-ethnography was felt to be most appropriate as an initial way of drawing together the current research. The combination of approaches in meta-ethnography make it a comprehensive approach which can bring together common concepts whilst still recognising contradictions in the literature. The first six stages of meta-ethnography are described below and this doctoral thesis is one means of the seventh phase, that of expressing the synthesis.

Search Strategy. For the current review, an initial search was conducted on 10 May 2023 and the final search to check for any updates was carried out on 13 October 2023. Due to the paucity of literature looking at the impact of baby loss on both mothers and fathers, the search criteria were expanded to include both perinatal loss and the loss of a baby up to one year of age. Therefore, for the purpose of this systematic literature review, the term 'baby loss' has been used to describe a loss during any stage of pregnancy and up to the first year of life. Relevant qualitative research exploring the impact on both parents following baby loss was located by using the search terms shown in Table 1. Four databases including PsychInfo, PsychArticles, CINAHL and Medline were included in the search and the Preferred Reporting Items for Systematic Reviews and Meta-analyses (PRISMA) checklist was used (Page et al., 2021). The search found a total of 6,385 papers, an initial screen of titles and abstracts found 52 of these to be relevant. Detailed reviews of the remaining articles were

completed and found 19 studies to be eligible and relevant for inclusion in the systematic analysis.

Table 1

Search Strategy

Search terms	"perinatal loss" OR stillbirth OR "perinatal death" OR miscarriage OR "neonatal death" OR "baby loss" OR "infant loss" OR "infant bereavement" OR "child loss" AND parents OR couple
Databases	PyschInfo, PsychArticles, CINAHL, MEDLINE
Other search strategies	Individual searches were conducted from the reference lists of the papers already identified for inclusion. Other sources were also searched, including Google Scholar and Open Grey.

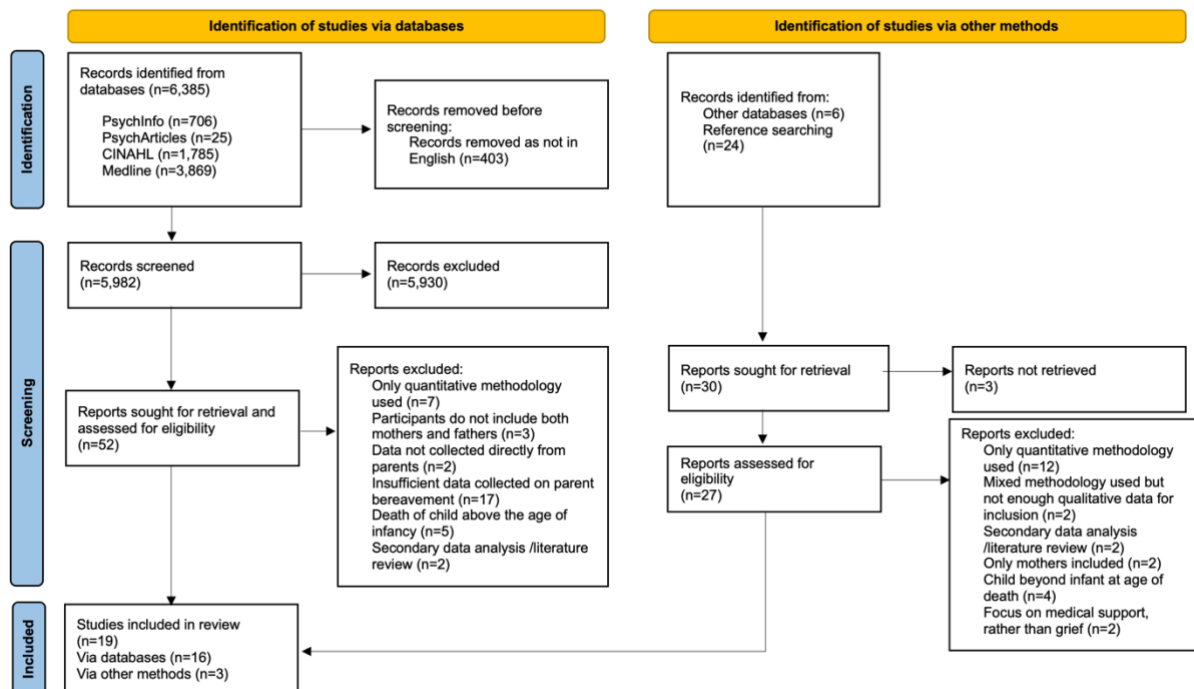
To ensure a thorough review of the existing literature was completed and to identify adequate literature for systematic review, further methods were used in addition to the initial search strategy. A hand search was carried out, screening the reference lists of eligible papers to identify additional studies; a citation search was also conducted on each of the eligible studies. A further search was conducted using Google Scholar. The literature was subject to the same level of critical analysis as the journal articles using the Critical Appraisal Skills Programme checklist (CASP; Critical Appraisal Skills Programme, 2018). In an

attempt to source further, unpublished studies, researchers in the field were contacted.

Following these additional searches, results were scrutinised and an additional 3 papers were included in the final literature review. The initial literature search is shown in Figure 1 using the PRISMA flow chart.

Figure 1

Initial search method showing the process of inclusion and exclusion of literature for systematic review using a PRISMA flow chart



Inclusion /Exclusion Criteria. For the initial screen of abstracts and titles, the SPIDER framework was applied to identify the sample, phenomena of interest, design, evaluation and research shown in Table 2 (Cooke et al., 2012). This found 52 studies to be eligible and the full articles were sourced.

Table 2*SPIDER Criteria for Study Eligibility and Inclusion (Cooke et al., 2012)*

Criteria	Definition
Sample	Both mothers and fathers who have experienced perinatal or infant loss
Phenomena of Interest	Both mother's and father's experiences of perinatal or infant loss, considering gender differences in parental bereavement
Design	Interviews and questionnaires including both parents, data collected separately or conjointly from mothers and fathers
Evaluation	Views, experiences, narratives
Research	Qualitative

The full texts of 52 studies were screened using the following, more comprehensive inclusion and exclusion criteria. First, they explored both mother's and father's experiences of bereavement by baby loss. Baby loss was defined as loss due to miscarriage, stillbirth, neonatal death, and up to the first year of life. One study looking at parental bereavement above the age of one was included as most participants experienced baby loss and the data was separated so that only this data could be analysed for the current review (Gudmundsdottir & Chesla, 2006). The literature did not always separate mother's and father's experiences but due to the lack of research in this area, it was decided to include this data. Studies exploring the impact of baby loss on only mothers, or only fathers were excluded due to the large skew of data looking only at mothers. If this literature were to be included, the review would be

disproportionately saturated by maternal views. Studies exploring parental experiences from the second-hand perspective of community leaders or healthcare professionals were excluded. Finally, studies must have reported primary data using at least one qualitative research method such as interviews, open-ended questionnaires or focus groups. Mixed methods studies were included if the qualitative data was presented separately from the quantitative data and could therefore be analysed independently of one another. Literature reviews and other sources of secondary data analysis were excluded. With these criteria in mind, a total of 19 studies were included for systematic review. All searches, screening, and extraction were conducted solely by the researcher.

Critical Appraisal. Due to the interpretative and exploratory nature of qualitative research, it can be difficult to assess rigour within studies. Though qualitative studies often use systematic methods of coding data to draw out themes, this relies on the experience of the researcher and can therefore contain a degree of subjectivity. Therefore, debate exists around how best to critically appraise qualitative data or whether this can be done at all (Gunnel et al., 2020). However, consensus is emerging that qualitative research can be assessed for quality and critical appraisal tools have been developed to support this (Tod et al., 2021).

As recommended for synthesising qualitative evidence by the World Health Organisation, the CASP tool for qualitative research was selected to critically appraise and consider the eligible studies for synthesis (CASP, 2018; Long et al., 2020). An Excel spreadsheet was created by the researcher to consider the quality, according to the CASP tool, of each study. All studies identified as eligible were included for synthesis regardless of quality due to limited available research in the area of interest. However, critical appraisal of the studies, as assessed within the aforementioned Excel spreadsheet, was considered and provided a useful, systematic framework to read the studies and the quality assessment is

commented on throughout the results in order to guide the reader on the studies utility and contribution to the findings.

Data Analysis. The eligible studies have been coded by author, title, journal, research methodology and main themes, shown in Appendix A. By following Noblit and Hare's (1988) seven phases, results from these studies were considered in relation to one another and studies were then translated. These translations were then synthesised, considering any contrary evidence in the data, to create a line of argument. Categories were identified and evidence was provided for these using quotations from author interpretations of data, rather than the raw data presented in the selected studies (Sandelowski & Barroso, 2007). Some studies looked at specific experiences of parents in neonatal intensive care unit (NICU) and paediatric intensive care unit (PICU) wards and their needs from medical staff at the time of their child's death. In these cases, full texts were read but only results relevant to the current research question were coded and analysed for inclusion in this meta-ethnography.

1.3.2 Results

This meta-ethnography of the nineteen eligible studies identified nine overarching categories (Table 3). These categories were synthesised to identify three third order concepts and from this, a line of argument was constructed. The categories included gender roles in bereavement, gendered styles of grieving, distancing from social network, pushed apart or pulled together, grief as profound, impact on faith, confused identities, maintaining an ongoing relationship with the lost child, and parenting pre-existing and future children. The three third order concepts included maternal grief and practical masculinity, baby loss is a disruptive tragedy to the relational system, and empty parenting and family planning. For the purpose of this meta-ethnography, I have used the term to refer to a loss during pregnancy and within the first year of life. I have done this as the literature did not always separate out the data according to stage of loss. I would therefore be unable to link the findings to the

stage of loss. However, this does mean that some nuance in findings will be lost as it is unknown whether each finding would apply to all stages of loss.

Table 3*Contribution of Concepts From Individual Studies to Categories, Concepts and the**Line of Argument*

Line of argument:	Baby loss and adjustment to parental role expectations								
	Third order concepts:	Maternal grief and practical masculinity		Baby loss is a disruptive tragedy to the relational system			Empty parenting & family planning		
Categories:	Gender roles in bereavement	Gendered styles of grieving	Distancing from social network	Pushed apart or pulled together	Grief as profound	Impact on faith	Confused identities	Maintaining on ongoing relationship with the lost child	Parenting pre-existing and future children
Abboud & Liamputtong (2005)	*	*	*						*
Avelin et al. (2013)	*	*		*					
Brierly (2017)	*	*	*					*	*
Cacciatore et al. (2008)		*	*	*	*	*	*	*	*
Clark et al. (2021)		*	*	*	*		*		*
Currie et al. (2019)			*	*	*	*		*	*
Dickerson (2016)	*	*	*	*	*	*	*		
Gudmundsdottir & Chesla (2006)			*		*		*	*	*
Hamama-Raz (2010)	*	*	*	*	*	*	*		*
Hasui & Kitamura (2004)			*		*			*	
Hooghe et al. (2012)			*	*	*		*	*	*
Jones-Peebles (2012)	*	*	*	*	*	*			*
King et al. (2021)		*	*	*	*		*	*	*
Kofod & Brinkmann (2017)			*		*				
Kristvik (2022)		*	*	*	*		*	*	*
Lang et al. (2011)	*	*	*	*	*			*	
Nuzum et al. (2018)	*		*	*	*			*	*
Steele (2023)		*	*	*	*		*	*	*
Tanacioğlu-Aydın & Erdur-Baker (2022)	*	*	*	*	*	*			*

Gender Roles in Bereavement. Most studies found that parents felt, or perceived, mothers to be the most impacted by baby loss. This left fathers in a position of a supporting role; their focus being to support the mother, rather than consider their own grief. Abboud and Liamputtong (2005) found that “all the men mentioned that their role during the time of miscarriage was one of support” (p.7). Their interviews were conducted by a female researcher, and it must be considered whether this influenced fathers’ responses, feeling an affinity to empathise or relate with the researcher, placing her in a mother role, rather than putting their own needs first, which they may have done in a male-only environment. However, many other studies saw fathers take the role of supporter, whilst the mother was able to grieve (Avelin et al., 2013; Brierly, 2017; Dickerson, 2016; Hamama-Raz et al., 2010; Jones-Peebles, 2012; Lang et al., 2011; Tanacioğlu-Aydın & Erdur-Baker, 2022). It is important to consider whether this is a reflection of cultural and societal expectations or a real, felt difference in the grieving process. However, these studies were conducted across a range of cultural contexts including the USA, Canada, Sweden, Turkey and Palestine. The assumption that mothers are the most impacted by baby loss is likely due to the “physical reminders that the baby was gone” (King et al., 2021, p.157). However, many studies used language indicative of expectations or assumptions, rather than reality. For example, Avelin et al. (2013) stated “the mothers grief reaction was also expected to be stronger and of longer duration than the fathers” (p.525). When talking about the interview process, Kristvik (2022) stated that “fathers were just as emotional as their partners and just as prone to tears when talking about their loss” (p.498). It is therefore unclear whether fathers are actually in a position to take the supporting role, or whether this is just an expected role influenced by cultural ideals of masculinity, which fathers feel the need to participate in. It is clear from the paucity of research looking at father’s experiences of perinatal loss that society feeds into this notion of mothers being the grievers, and fathers being the supporters. King et al. (2021)

reported that even “some mothers worried that the staff forgot or did not care for fathers the way they did mothers” in hospital (p.157). This demonstrates that our healthcare system also feeds into this maternal focused narrative.

Similarly, Kofod and Brinkman (2017, p.525) clearly state that previous literature situates mothers as the primary mourners following baby loss. However, their findings do not go on to explicitly support this, and so I have not included the data as supporting this category. Though I feel the results do implicitly imply that they found mothers to be the primary mourners as the majority of quotations used and examples given have come from the female participants interviewed. It is difficult to know if this is a genuine reflection of the findings or whether the authors have been influenced by the wider societal discourse that leans towards mothers taking a primary position in perinatal loss literature.

Gendered Styles of Grieving. As well as gendered roles following baby loss, many studies found that mothers and fathers grieved in different ways. It is unclear whether there is causality between the two. Many papers found that women tend to grieve more externally, whereas men tend to grieve more internally (Steele, 2023). Hamama-Raz et al. (2010) found that “men repress their painful emotions and resort to rationalisation” (p.254). Hamama-Raz et al. (2010) interviewed couples within a religious Jewish community, which may influence men to fit a more traditional masculine mould where repression of emotions is valued and important. This finding was also reflected in their difficulties with recruitment as 10 of 15 couples dropped out of the research when contacted a second time, the researchers reported that this was usually due to the husband objecting to participation. This suggests that males from this community were reluctant to talk about or share their experiences of bereavement. Tanacioğlu-Aydın and Erdur-Baker (2022) found that “men talked with their friends about more superficial issues, such as which hospital they should go” to, rather than how they were

feeling (p.2241). This study was done within a Turkish community which may also hold a more traditional view of masculinity. Abboud and Liamputtong (2005) also found that men were unable to talk about and outwardly express their grief “due to social expectations of the male role” (p.8). Abboud and Liamputtong recruited couples that all lived in Melbourne, Australia, and were Christians. It is unclear whether this religious demographic may also influence these participants to lean towards more traditional views of masculinity. However, these participants are exposed to Western cultures and are therefore likely to reflect Westernized views, rather than more typically traditional cultures. These views of needing to be strong and suppress their emotions were also shared by fathers interviewed by Jones-Peebles (2012). Lang et al. (2011) found that “women needed to talk about the loss for a longer time than men” (p.190). This study was conducted in Montreal, and though no information relating to religious orientation was captured, Montreal may be more reflective of a more contemporary view of masculinity and still found that fathers spoke less about their bereavement and grief than mothers.

When grief was expressed by men, the research found that their thoughts tended to be more action-oriented and future-focused than women (Cacciatore, 2008). Fathers struggled in their attempt to “control/fix the situation”, causing them to feel helpless (Clark et al., 2021, p.265). This helplessness and need to fix may also be synonymous with the male role as a supporter following baby loss. It appeared that men often sought more activities of distraction, such as returning to work, than women (Avelin et al., 2013; Jones-Peebles, 2012; Kristvik, 2022). Returning to work to help with grieving and to provide distraction was not exclusive to men as Steele (2023) found that both men and women desired to return to work as a distraction for their grief. Clark et al (2021) found that more women than men did this. However, across the literature, this was largely found to be a more typically male response.

The research identified that women were more likely to and felt more of a need to talk about their loss with others. This was shown in talking to friends and family. Brierly (2017) found that women were more likely to share their experiences online, using social media platforms to communicate about their loss experiences. A factor that often appeared to be unique to mothers was a sense of self-blame. Multiple studies revealed that “women tended to blame themselves for the loss” (Abboud & Liamputtong, 2005; Brierly, 2017; Dickerson, 2016; Kristvik, 2022; Nuzum et al., 2018; Tanacioğlu-Aydın & Erdur-Baker, 2022, p.2241; Steele, 2023). Some mothers even began to change their behaviours, such as increasing exercise or rest in response to feeling responsible for the loss (Nuzum et al., 2018). Hamama-Raz et al. (2010) identified that women from a Jewish community viewed their perinatal loss as a personal failure, which caused self-judgement and intensified their emotional experiences. However, Hasui & Kitamura (2004, p.250) found that all parents expressed feelings of “responsibility for their child’s death”. This study was conducted in Japan and may be reflective of a cultural tendency to internalise blame (Bear et al, 2009). Jones-Peebles’ (2012) sample included 10 participants, of which 8 identified as ‘Caucasian’ or ‘White’ and concurred that both mothers and fathers felt a sense of guilt for their loss. However, they found that this feeling reduced over time and did not explore in depth at how this feeling resonated specifically with women.

In contrast to the gender differences found in the expression of grief, King et al. (2021) found that “mothers and fathers reported many similar emotions and initial reactions to the loss” (p.156). It may be that men’s and women’s grief is similar at the initial stages of grief and then becomes more disparate as time goes on. In support of this, multiple studies mentioned that both men and women had an initial reaction of shock and helplessness when hearing about the news of their loss (Cacciatore et al., 2008; Hamama-Raz et al., 2010; King et al., 2019; Kofod & Brinkman, 2017; Steele, 2023). Therefore, it may be that men and

women experience similar grief reactions but cope with and express these in different ways, perhaps according to their gendered roles of grieving.

Distancing From Social Network. Eighteen of the nineteen included studies found that parents experienced baby loss as having an impact on their social network. Many studies found that parents will avoid social situations following the loss of their child. Kristvik (2022) identified that parents felt “vulnerability in social situations” (p.467). The literature tended to report social avoidance following baby loss as a way for parents to protect themselves, and this was a felt need for a number of reasons. Some parents felt they had no capacity for others while grieving (Kristvik, 2022). Similarly, others felt so consumed by bereavement that they felt unable to engage in social situations where they were required to consider other topics of conversation (Kristvik, 2022). Currie et al. (2019) on the other hand, found some parents tended “to shut people out or avoid opening up about their grief” (p.338), so they were avoiding others in order to not talk about their loss. Hasui and Kitamura (2004) found that parents worried about other’s reactions to their loss. Some of the research showed that parents avoided social situations specifically to avoid new parents or pregnant people (Clark et al., 2021; Nuzum et al., 2018). Nuzum et al. (2018) reported that “encountering other parents and babies evoked jealous feelings and painful reminders of the reality of their loss” (p.7). Nuzum et al. (2018) found that some parents felt shame regarding their loss when seeing other parents. Brierly (2017) found a similar pattern replicated by mothers in their online behaviour, as several mothers ‘unfollowed’ other mothers of young children and pregnant women whilst grieving. Brierly did not say that this was also true of fathers, so this may be a difference in the impact of baby loss. However, similarly to the avoidance of other parents and pregnant people in real life, Brierly reported that this was a helpful function for coping with bereavement when using social media; a parent’s way of protecting themselves whilst grieving.

Much of the literature discussed or alluded to the disenfranchised nature of baby loss and other people not knowing how to respond to grieving parents. This appears to have also impacted parents' ability and will to interact with their social network. For some, this caused tension in relationships as multiple studies reported that couples had experienced negative or harmful comments from others in their social network (Abboud & Liamputtong, 2005; Currie et al., 2019; Jones-Peebles, 2012; Kristvik, 2022; Tanacioğlu-Aydın & Erdur-Baker, 2022). With limited information, it is not possible to know for certain, but it may be that these comments have not been said with mal intent, but rather due to a lack of understanding of the impact of baby loss and therefore not knowing how to respond more helpfully. Even when there were no directly harmful comments made, Tanacioğlu-Aydın and Erdur-Baker (2022) commented on one mother's experience saying that her baby loss was "not deemed important by most of the people in her life" (p.2243). This appeared to be a common experience as many studies found that baby loss was often diminished, or even unacknowledged by parents' social network (Hooghe et al., 2012; Kofod & Brinkman, 2017; Kristvik, 2022; Lang et al., 2011; Tanacioğlu-Aydın & Erdur-Baker, 2022; Steele, 2023). The societal discourse causing these reactions inhibits parents from receiving the support that they need from their social network.

The disenfranchised nature of baby loss also meant that research found parents struggling with a lack of guidance on how to grieve their child (Clark et al., 2021; Kofod & Brinkman, 2017; Lang et al., 2011). Some studies found parents did not know how to share the news of their loss and struggled with how to do this (King et al., 2021; Kofod & Brinkman, 2017; Kristvik, 2022; Lang et al., 2011). This further contributed to the avoidance of and tension during social interactions. Some studies revealed that some parents preferred to keep the news of their loss private (Abboud & Liamputtong, 2005; Lang et al., 2011; Nuzum et al., 2018). Others, such as some of the parents interviewed by Brierly (2017)

chose to share the news of their loss on social media so that they were able to manage how much or little to share and were able to share the news with a large network at once. It seemed that some parents were not only managing their own emotions whilst grieving but also the feelings of others. Kofod and Brinkman (2017) wrote that the “assumed limits of other people regarding how much they can tolerate hearing about the loss can pose a dilemma for the bereaved parents” (p.528).

The literature demonstrated that these factors led to parents feeling isolated by their bereavement (Clark et al., 2012; Currie et al., 2019; Dickerson, 2016; Gudmundsdottir & Chesla, 2006; Hamama-Raz et al., 2010; Hooghe et al., 2012; Kristvik, 2022; Lang et al., 2011; Steele, 2023). Clark et al. (2021) summarised the systemic impact of baby loss well as they “noted strained social relationships following the death, difficulty relating to others, and isolation” (p.265).

Some of the research found parents who had positive experiences of their social network (Abboud & Liamputtong, 2005; Brierly, 2017; Jones-Peeples, 2012). When this was the case, parents had noted how helpful this had been in their ability to cope with infant bereavement. This highlights the need to increase awareness of the impact of baby loss so that parents are not met with invalidating or diminishing responses to their loss. The research showed the importance of a couple’s social network as a source of support and the positive impact of a couple’s network providing a space to talk about their child (Abboud & Liamputtong, 2005; Cacciatore et al., 2008; Currie et al., 2019; Dickerson, 2016; Jones-Peeples, 2012; King et al., 2021; Kristvik, 2022; Tanacioğlu-Aydın & Erdur-Baker, 2022; Steele, 2023).

Pushed Apart or Pulled Together. As well as impacting parents’ relationships with their wider network, the literature showed that baby loss had an impact on the relationship

between the couple. King et al. (2021) revealed mixed results, they found that “most couples discussed how stillbirth could bring a couple closer together or push them apart” (p.158). They did, however, find that for most of the couples they interviewed, the bereavement brought them closer together. King et al. (2021) interviewed couples conjointly and a part of their inclusion criteria stipulated that participating couples must still be together. Therefore, though they found mixed results, their findings are likely to be biased toward couples that were able to work through the challenges put upon them by baby loss. Even participants who experienced a negative impact on their relationship were able to work through this and stay together. King et al. (2021) recruited their participants through social media and support groups; unlike other included studies which recruited via hospitals. Therefore, they are likely to have recruited participants who have received support around their loss, which may have allowed the couple to grieve together more easily than those attempting to navigate their loss alone.

These mixed results were reflected in the rest of the included literature, too (Avelin et al., 2013; Cacciatore et al., 2008; Clark et al., 2021; Dickerson, 2016; Hamama-Raz et al., 2010; Jones-Peebles, 2012; Kristvik, 2022; Nuzum et al., 2018; Tanacioğlu-Aydın & Erdur-Baker, 2022). Only a few studies mentioned only negative impacts on relationships (Currie et al., 2019; Lang et al., 2011) and only one included study mentioned only positive impacts on relationships (Hooghe et al., 2012). As the included literature has been conducted across a range of cultures, it can be concluded that baby loss is highly likely to impact a couple’s relationship and that this impact can be either positive or negative, depending on the individual couple and their unique set of circumstances.

It seemed that where research found that baby loss had placed “huge strain on the relationship” (Kristvik, 2022, p.499), this was largely caused by the partners grieving in

different ways (Avelin et al., 2013; Cacciatore et al., 2008; Currie et al., 2019; Hamama-Raz et al., 2010; King et al., 2021; Lang et al., 2011; Nuzum et al., 2018; Tanacioğlu-Aydın & Erdur-Baker, 2022; Steele, 2023). Lang et al. (2011) found that couple's different ways of grieving meant that they had different expectations of their partner, which impacted the amount of support they were able to give each other. Tanacioğlu-Aydın and Erdur-Baker (2022) found that some couple's grief reactions meant that they created an emotional barrier, which made it difficult for their partner to be close and for others, their grief was so intense that they were unable to support one another. Nuzum et al. (2018) also found mixed results but found that parents struggled "to communicate with their partner about their feelings of grief" (p.8) and therefore were also unable to support each other. They did find some parents whose relationship was positively impacted by their experience of bereavement; however, this was fewer than those negatively impacted. It seems that differences in styles of grieving affect spouses' ability and capacity to support one another, which then can negatively impact their relationship, pushing them apart.

Where the research showed baby loss bringing couples closer together, it was clear that the relationship provided an essential source of support in parent bereavement. Hooghe et al. (2012) conducted a case study looking at one couple's experience following the death of their 6-month-old daughter to leukaemia. They identified an oscillating process of confronting and avoiding the pain of grief that the couple went through together. This closely examined account of a couple's grief highlights the dynamic nature of grief and the changing needs of the griever. This in turn reveals the challenge and sensitivity needed by partners to support one another following baby loss. Tanacioğlu-Aydın and Erdur-Baker (2022) found that baby loss simply caused couples to spend more time together, which for some was helpful in healing. This shows a much simpler way in which baby loss can bring a couple closer together.

Grief as Profound. Though the literature identified many nuances to the impact of baby loss on parents, almost all of the included studies described baby loss as a devastating life event, with long-term implications for parents. Many studies described bereaved parents experiencing symptoms similar to that of depression, such as “insomnia and concentration problems” (Kristvik, 2022, p.500). For many parents whose experiences were examined in the literature, grief was profound and interfered with their daily functioning. Many parents required time off work to cope with their bereavement. Some fathers needed more time off of work than is automatically permitted, as similarly to paternity leave, it appears that fathers are often granted less time off of work than mothers following perinatal loss (Kristvik, 2022). However, Steele (2023) found that even when fathers were granted “as much time as they needed”, on average, they still took less time than mothers given the same offer (p.96). Parental grief was so all-consuming for some parents that they felt guilt for any feelings of happiness, as though this would be disrespectful to the child they lost (King et al., 2021; Kofod & Brinkman, 2017). Hasui and Kitamura (2004) found that parental grief was so painful that none of the parents could manage their emotions alone.

Some studies considered the timeline of grief following baby loss and found that the impact of grief was most intense at the start, becoming more tolerable over time (Clark et al., 2021; Currie et al., 2019; Jones-Peebles, 2012; King et al., 2021). However, all agreed that “the pain of the loss never went away completely” (Currie et al., 2019, p.336). Many of the studies recognised that the parents “grief intensified when they encountered reminders, [such as] anniversaries of birthdays” (Clark et al., 2021, p.264).

Despite the gravitas of baby loss on the lives of parents, some studies revealed personal growth following baby loss. Some parents felt increased gratitude and empathy following their loss and others felt that their bereavement brought them closer to God

(Cacciatore et al., 2008; Clark et al., 2021; Jones-Peebles, 2012). Others felt that grief strengthened their relationships. However, for all of the studies that noted some growth following bereavement, this did not take away from the severe and profound impact that baby loss had on both parents.

Impact on Faith. Given the profound nature of baby loss and the known existential realities evoked by bereavement, it may be of no surprise that a third of the included studies discussed the impact on the parent's faith. Some found that some parents used their faith as a tool for coping with the loss (Currie et al., 2019; Dickerson, 2016; Jones-Peebles, 2012; Tanacioğlu-Aydın & Erdur-Baker, 2022). Tanacioğlu-Aydın and Erdur-Baker (2022) found that how parents understand their loss was influenced by their religious beliefs and for some, this allowed them to give meaning to their loss. The belief that the "lost baby will wait for them in heaven" helped some parents to cope with the impact of bereavement, while others felt that religion provided a sense of acceptance, as their experiences were led by God and so not in their own control (Tanacioğlu-Aydın & Erdur-Baker, 2022, p.2242). The aim of Tanacioğlu-Aydın and Erdur-Baker (2022) was to describe perinatal loss experiences from a sociocultural perspective in a Turkish community. Therefore, it is important to consider that these views may be specific to this community and may not be shared more widely.

Currie et al. (2019) explored parent bereavement following infant deaths occurring within a NICU in South-eastern United States. They found that parent's faith either strengthened or weakened following their loss. Some participants experienced "spiritual suffering when trying to make sense of the loss" and found it difficult to keep their faith when living with the impact of grief (Currie et al., 2019, p.336). However, other participants included in this study "became closer to God and grew spiritually" (Currie et al., 2019, p.336). It seems that participants who felt their faith strengthened were those who used their

beliefs as a way of coping. Though this study recruited both male and female participants, the final sample included 7 mothers and 3 fathers and all the included quotes demonstrating the impact of loss on faith were by mothers. Therefore, it cannot be concluded from this study alone that baby loss has an impact on the faith of fathers, as it does mothers. Cacciatore et al. (2008) also considered the impact of loss on parents' religious or spiritual beliefs and also found that parent's faith was either strengthened or weakened following perinatal loss. Cacciatore et al (2008) interviewed sixteen cohabiting, heterosexual couples; and therefore, interviewed an equal number of mothers and fathers. They found that both "bereaved mothers and fathers seemed to struggle with faith" (p.360), as they re-evaluated their beliefs to process their loss. They found that for some parents, this re-evaluation led to a strengthening of their faith. It therefore does seem that for parents with a faith, this is likely impacted following baby loss, though it is not clear how or in which direction this will be.

Hamama-Raz et al. (2021) revealed "faith-related doubts among the women in contrast to the solid faith in God demonstrated by their husbands" (p.254). They suggested that mothers may perceive their loss as abandonment by God, whereas some fathers may "interpret the loss as God's way of protecting rather than neglecting them" (p.257). This suggests there may be gender differences in the way parents make spiritual meaning of their which may influence their experiences of the impact of baby loss.

As can be seen in Table 3, the majority of the included literature did not mention an impact on parent's faith. It is hard to know whether this is influenced by the participant demographics of each study, such as whether they are mainly interviewing parents without faith. Alternatively, this may be influenced by the author's own religious orientation, as to whether they paid particular attention to this area or whether this was included in the interview schedules. Therefore, though it was only mentioned in four of the fifteen included studies, it felt important for participants where religion was a part of their experience.

Confused Identities. Over a third of the included studies found that parents were left confused regarding their identity as parents following baby loss (Kristvik, 2022; Clark et al., 2021; King et al., 2021; Lang et al., 2011; Hamama-Raz et al., 2010; Gudmundsdottir & Chesla, 2006; Cacciatore et al., 2008; Dickerson, 2016; Steele, 2023). Hamama-Raz et al. (2010) found that this was a particularly pertinent experience for mothers, writing for one mother that she felt the “loss of a significant component of her self-identity” (p.256). This study did not find fathers experiencing the same, personal doubts regarding their identity. The women interviewed by Hamama-Raz et al. (2010) and Dickerson (2016) perceived the loss of their babies as a personal failure, which caused them to question their utility as women and as wives. These thoughts may be bound in cultural beliefs regarding the female role, and what it means to carry and to lose a child within the Jewish community. Other studies found that both mothers and fathers were facing confusion over their identity as parents following baby loss. Cacciatore et al. (2008) described the dilemma for some parents as “a distinct identity crisis” (p.360). King et al. (2021) and Dickerson (2016) revealed that parents felt as though they were missing a part of themselves following baby loss.

Gudmundsdottir and Chesla (2006) aimed to understand the habits and practices developed by families following the sudden loss of their child. For the majority of the families interviewed, their child had died below the age of 6 months old. They found that one parent had kept the child’s bedroom unchanged and that this signified to her “that she, indeed, had been a mother” (p.151). It seems that families have different ways of attempting to keep together their identity as parents and this is important to them in coping with baby loss. This confusion of identity may also feed into parents’ avoidance of social situations, as they are not quite sure how to present themselves and which role they now occupy. In line with this, Clark et al. (2021) found that some parents felt they “no longer fit in with other parents” (p.265). Though the exact reasoning is unclear, the studies that discussed baby loss

as causing a confusion in identity for the bereaved parents, often linked this to a sense of further isolation for these parents.

Maintaining an Ongoing Relationship With the Lost Child. Multiple studies revealed that parents maintained an ongoing relationship with their child following their death (Gudmundsdottir & Chesla, 2006; Hasui & Kitamura, 2004; Hooghe et al., 2012; King et al., 2021; Nuzum et al., 2018; Steele, 2023). For many, this relationship was ongoing years after the death of their child and irrespective of whether the parents had gone on to have more children or already had existing children. Parents demonstrated the importance of keeping the lost child as a part of the family (Cacciatore et al., 2008; Gudmundsdottir & Chesla, 2006; Hooghe et al., 2012; Nuzum et al., 2018). In line with this, many parents pointed out the need for personhood of their lost baby (King et al., 2021; Kristvik, 2022; Nuzum et al., 2018). This was important to parents in a range of situations, from dealing with practical issues following the news of their loss in hospitals to the way their child is referred to in social settings with friends and family. As well as personhood, it felt important for parents' ability to cope with their bereavement that their child continued to be acknowledged. This was mirrored when thinking about the impact of baby loss in parents' social networks, where their child was not acknowledged tended to cause ruptures in their relationships.

In order to maintain this ongoing relationship, where their child was not physically present, parents often used other physical representations of their child. They cared for and preserved these representations as symbols of their relationship with the child. For example, keeping a bedroom perfectly preserved or keeping hair cuttings safe. Some parents developed rituals or traditions to maintain their relationship with their child (Currie et al., 2019; Gudmundsdottir & Chesla, 2006). Gudmundsdottir and Chesla (2006) described one couple as developing "many practices that in one way or another connected them to" their lost child (p.153). Many of the studies referred to these physical representations and rituals as ways of

preserving and keeping the memory of their child alive (Brierly, 2017; Currie et al., 2019; Gudmundsdottir & Chesla, 2006; Kristvik, 2022). Hasui and Kitamura (2004) suggest that parents maintain their relationship with their child by seeing the changes in their own personalities caused by grief, as proof of the baby's existence.

For many parents, grief was harder on significant dates and milestones, such as birthdays or anniversaries (Brierly, 2017; Clark et al., 2021; King et al., 2021; Lang et al., 2011; Steele, 2023). At these times, it seems that parents drew on their physical representations or rituals more in order to connect with their lost children in these more difficult periods. For some, connecting with their lost child was a way of continuing to parent them. Nuzum et al. (2018) described parents regretting not taking more opportunities to parent their baby when they were still alive. Therefore, taking these opportunities to parent following the death of a child makes sense as a way of coping with this type of bereavement. Similarly, some parents found ways of connecting to their lost children by taking on projects or charity work that related to their child in some way, even such as participating in the included research (Hooghe et al., 2012; Steele, 2023). Gudmundsdottir and Chesla (2006) and Steele (2023) found that honouring important dates was also a way for parents to continue to parent their lost child. For example, some parents would visit their child's grave and sing to them to mark important dates. The couple discussed in Hooghe et al.'s (2012) case study found that even just talking about their lost child acted as a way "to keep their daughter close to them, to honour the child's memory, and keep her present in their lives" (p.1226). Hooghe et al. (2012) also discussed the conflict that this brought to the couple. Though keeping their daughter present was an important process for them, it was also one that elicited great amounts of pain. Therefore, the couple found themselves oscillating between seeking closeness to their daughter through private rituals and thinking of her; then also needing to avoid this at times to protect themselves from the pain of their grief. Therefore, it appears that

long after baby loss, parents make efforts to continue to parent the child that died and to preserve their memory of this child. Important facilitators of this are for others to support parents in this by continuing to give personhood to and acknowledge the child that has died.

Parenting Existing and Future Children. The literature showed that for many couples, the impact of baby loss influenced their roles as parents to their existing and future children, too. Clark et al. (2021) explored parent experiences following the death of a child in a NICU at least three months prior to the interview. Fathers felt powerless to help or fix the situation when losing their child, which understandably led to anxieties around losing other children. These anxieties resulted in “increased protectiveness and hypervigilance for other children in the home” (Clark et al., 2021, p.265). This response may be influenced by the potentially drawn-out experience of having a baby in NICU and visiting this baby whilst being powerless to protect or make the child well again. Parents may have a different experience to when losing a child by miscarriage or stillbirth where news of the loss may come suddenly and as a shock to parents. It may be that this time coming to terms with an baby’s death within the first year of life may add to feelings of helplessness and increased anxiety for other children. However, many other studies also found that parents experienced heightened anxiety regarding future pregnancies and other children as they worried about other children dying (Abboud & Liamputtong, 2005; Cacciatore et al., 2008; Hooghe et al., 2012; Tanacioğlu-Aydın & Erdur-Baker, 2022; Jones-Peeples, 2012).

Gudmundsdottir and Chesla (2006) interviewed multiple members of 7 families who lost children suddenly and unexpectedly. The children ranged from 3.5 months old to 9 years old, but 5 of the 7 children were under 6 months old when they died. This study found that some mothers strongly desired to become pregnant again, very soon after their loss. For some men, baby loss stopped them from wanting to try for another child for fear of another loss (Abboud & Liamputtong, 2005). However, it appeared that despite this fear, many

couples became or desired to become pregnant again (Abboud & Liamputtong, 2005; Brierly, 2017; Currie et al., 2019; Gudmundsdottir & Chesla, 2006; Hooghe et al., 2012; Kristvik, 2022; Tanacioğlu-Aydın & Erdur-Baker, 2022). Currie et al. (2019) found that “eight of the ten parents had another child after the loss of their infant” (p.336). The literature showed that for many couples, the thought of having another child following baby loss gave parents hope and helped parents to cope (Abboud & Liamputtong, 2005; Brierly, 2017). For some parents, having another child after their loss helped parents to cope by giving them a renewed sense of purpose (Currie et al., 2019). For others, having another child helped parents to make meaning of their loss which appeared helpful in coming to terms with their bereavement (Gudmundsdottir & Chesla, 2006).

Though many parents included in the literature found that having another baby after their loss was a positive, helpful experience, this was not always straightforward. The literature revealed that going on to have another child following baby loss was a complex experience which could bring up difficult emotional challenges for families. It was commonly found that subsequent pregnancies were fraught with fear (Abboud & Liamputtong, 2005; Hooghe et al., 2012; Tanacioğlu-Aydın & Erdur-Baker, 2022; Steele, 2023). Other studies revealed that future pregnancies were not only filled with fear but also with sadness (Hamama-Raz et al., 2010; Kristvik, 2022). Hamama-Raz et al. (2010) found that this was not only in the pregnancy that followed the bereavement, but every subsequent pregnancy. One mother expressed that each routine check-up during future pregnancies triggered thoughts of the child that could have been and reconnected her with the loss and sadness. Gudmundsdottir and Chesla (2006) discussed some families’ experiences of making room for their new baby, which can typically be an exciting and precious time for parents. However, for these families, preparing the lost baby’s room to make space for a subsequent baby felt like “dismantling the memorial” that had been preserved to honour their lost child

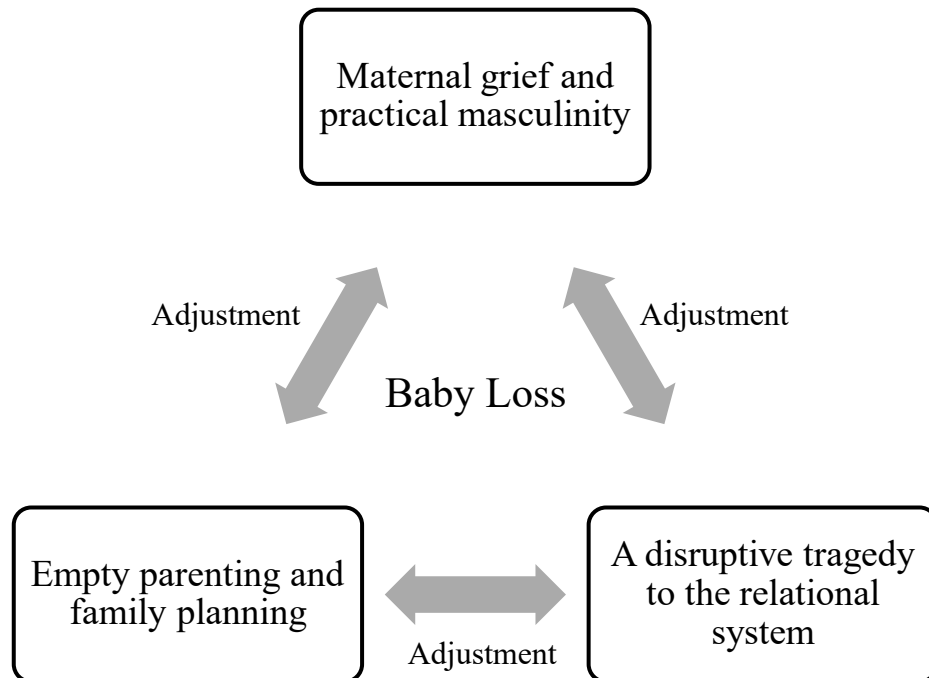
(p.153). This was seen as a necessary but painful experience for parents. For some, this took away a space that parents had previously used to feel connected with the child they were grieving. Even following the birth of a subsequent child, Gudmundsdottir and Chesla (2006) found that parents felt that their new baby brought great joy but took them away from connecting with the child they lost. The current study aims to explore this further by exploring the impact of prior perinatal loss on parenting subsequent children.

Line of Argument: Baby Loss and Adjustment to Parental Role Expectations.

The line of argument is that baby loss impacts parents' roles in multiple domains (Figure 2). These domains include their roles as parents, as men or women, as romantic partners, as friends, as a person of faith and as a griever. Following baby loss, it is likely that parents will be adjusting in all of these areas and that this may continue long after the bereavement and after the birth of subsequent children, should the parents become pregnant again. This is a holistic view of the impact of baby loss and does not suggest an order to these changes, as the adjustments are interlinked and may occur simultaneously. Different areas of adjustment may be more prominent for different parents, depending on their personal context and roles prior to baby loss. This will also be influenced by the parents' cultural context and wider societal discourse. Though some areas of adjustment are likely to restabilise after some time, it is unlikely that they will be the same as prior to parents' experience of baby loss.

Figure 2

Line-of-Argument: Baby Loss and Adjustment to Parental Role Expectations



Maternal Grief and Practical Masculinity. It appears that men and women assume different roles following baby loss which may shape how they adjust to the loss. This may be influenced by parents adhering to traditional gender norms elicited by the wider societal context, as well as biological factors such as a mother's physical response to baby loss. Father's roles were less emotional and likely to be drawn to practical, task-oriented coping strategies. However, it may be useful for fathers to be offered a space to talk about their experience of not only their grief but also how it feels to be taking on the role of support for their partner and whether they feel acknowledged as a grieving parent. It feels important to acknowledge the impact of baby loss, especially for fathers, who may otherwise fall through the gaps in the typical support systems available to parents. Fathers may feel more able to

engage with support away from their partner, or with other fathers, where they do not need to assume the role of supporter.

As would be assumed by the so far dominant focus on mothers in baby loss and baby loss literature, mothers were illustrated as the primary mourners following baby loss. For mothers, it may be helpful to think about their embodied experience of loss, how they are internally making meaning of this, and exploring feelings of responsibility and shame.

A Disruptive Tragedy to the Relational System. Whilst parents attempt to navigate their new roles within their relationship, baby loss consistently impacts couples on a systemic level. Baby loss can be disruptive to a couple's relationship with one another, their social network, and their faith. However, it cannot be guaranteed in which way bereavement is disruptive. For some their system was disrupted for the better, bringing them closer to their partner or faith. Others became isolated from their social network, their partner and questioned their faith; significantly challenging their place in their relational world. The disenfranchised nature of baby loss serves to intensify disruption to parents' social networks as they tend to move away from the bereaved parent to avoid difficult conversations, further alienating the bereaved parent.

Empty Parenting and Family Planning. Embedded in the literature was the impact of baby loss on the family; the family left behind and the family to be. As well as parents questioning their identity in terms of how they relate with others, bereaved parents also adjust to their own sense of self. New parents will have begun to build their identity as parents, incorporating new hopes and dreams for the future of how they will care for and raise their child. When baby loss occurs, this sense of self can become shattered. It is hard to put into words this complex process of adjustment, I have chosen 'empty parenting' as bereaved parents are still parents, but without their child to enact these new roles. Navigating this can

add to the disruption of parent's relational worlds. Often parents will find ways to continue to parent their lost child, through rituals or storytelling.

When couples have pre-existing children, they may be adjusting their parenting as the loss is likely to cause increased anxiety regarding the safety of their other children. This may affect the family system, as children may also become more anxious. Parents also feel more anxious regarding future pregnancies. For some, this adjustment is too challenging, and they would rather avoid the risk of further loss by not becoming pregnant again. This decision may be linked to men's feelings of helplessness of not being able to control the situation and women's feelings of self-blame, questioning their ability to be mothers.

1.3.3 Discussion

This systematic review of the literature highlights the widespread and long-lasting impact of baby loss on both parents. Though there were differences seen in the way that baby loss can affect mothers and fathers, both were impacted significantly. The differences appear to partially support previous research that fathers lean towards restoration-oriented coping, whilst mothers engaged in more loss-oriented coping (Alam et al., 2012). This could be seen in fathers engaging in more action and distraction behaviours, whilst mothers spoke and thought about their grief more (Kristvik, 2022; Avelin et al., 2013). However, this was not consistent, and it is unclear if this is reflective of parents' actual grieving process, or a behavioural response to societal expectations to adhere to traditional gender norms. It is unclear whether fathers would grieve differently in the absence of traditional masculinity pushing them to suppress emotions and be strong to support the mother. Despite the inclusion criteria stipulated for this review being aimed at showing the impact of baby loss on both parents; the data was still biased towards exploring maternal experiences. Where research did not specifically recruit couples conjointly, they found that more females than males participated. It is unclear whether this is as a result of the wider societal discourse allowing

mothers to grieve whilst fathers support them, or of the societal discourse of masculinity, discouraging males from participating in research where they are invited to talk about their experiences and explore their feelings in relation to these. It feels important therefore that further research makes an effort to be more inclusive of the narrative of fathers. Interviewing couples conjointly feels like a helpful way of doing so but comes with its own caveats as the research becomes biased toward couples that have stayed together. Despite this bias, King et al. (2021) was still able to see the effect of perinatal loss on the couple was not straightforward and either pushed couples apart or pulled them closer.

The literature also highlighted the disenfranchised nature of parental bereavement, specifically in the instances of perinatal loss. This is supported by other research showing that societal norms trivialise this form of grief, especially in the case of miscarriages (Fredenburg, 2017; Lang et al., 2011). This not only acted as a barrier for parents accessing meaningful support through their social network but even elicited hurtful comments and further isolated parents in their time of need (Abboud & Liamputtong, 2005; Tanacioğlu-Aydın & Erdur-Baker, 2022; Currie et al., 2019; Kristvik, 2022). Furthermore, despite legislation, it appeared that healthcare professionals are not always providing a supportive environment following perinatal loss and are not always involving fathers as they should be (King et al., 2021). It was viewed as helpful and important to parents that their baby was permitted personhood and acknowledged by others. Therefore, it would be helpful for future research to explore perinatal loss, specifically, as this appears to be the most disenfranchised form of parental bereavement. This would be especially important to be inclusive of fathers who appear to be viewed as supporters, rather than allowing space for their own grief. Research by Mulvihill and Walsh (2014) also showed that parents are not always given the support that would be expected following other types of bereavement, due to the disenfranchised nature of baby loss.

The included research showed the importance of parents maintaining an ongoing relationship with their lost child, whether this be through rituals or physical representations of their child (Brierly, 2017; Currie et al., 2019; Gudmundsdottir & Chesla, 2006; Kristvik, 2022). This supports the notion of continuing bonds being an important part of the grief process, as suggested by Davies (2004).

The literature showed that baby loss impacted subsequent pregnancies (Abboud & Liamputtong, 2005; Hamama-Raz et al., 2010; Hooghe et al., 2012; Kristvik, 2022; Tanacioğlu-Aydın & Erdur-Baker, 2022). However, though some research looked at the impact of infant bereavement beyond this, following the birth of a subsequent child, none of the included literature explored this in any depth. The long-lasting impact of baby loss and the increased struggle at significant anniversaries indicate that having a subsequent child would be a clear reminder of parent's loss (Brierly, 2017; Clark et al., 2021; King et al., 2021; Lang et al., 2011). Though this is likely to bring great joy, as some research highlighted the thought of future children gave parents hope, the research also revealed that this brought about complex and difficult emotions for parents (Abboud & Liamputtong, 2005; Brierly, 2017). It seems that parents' desire to become pregnant again, despite conflicting emotions may be linked to the concept of meaning-making. Stroebe and Schut (2001) suggest that meaning-making is used to cope following life-changing events, such as bereavement. Finding meaning after baby loss and regaining a sense of purpose has been shown in both quantitative and qualitative research to be associated with better outcomes for parents (Lichtenthal et al., 2010; Wheeler, 2001). The literature highlighted that the process of becoming pregnant again or having a child after loss gave meaning to their loss and gave parents a renewed sense of purpose, just as Stroebe and Schut stipulate. It feels important to explore the impact of baby loss for parents beyond their subsequent pregnancy, to following

the birth of subsequent, healthy children. It is curious to know whether meaning-making in this sense does indeed lead to positive outcomes for parents.

As demonstrated by the line of argument, the clinical implication for this meta-ethnography is that clinicians working with bereaved parents should be aware of and consider exploring the impact on these individuals in the listed areas of adjustment (see Figure 2). As the literature reveals the impact can be different between individuals, it is important to explore which areas and in which ways each role has been destabilised. It may also be helpful to step beyond a Western lens of health care and integrate community resources and spiritual leaders in supporting bereaved parents, as it is shown that their relational system is deeply disrupted. It may be helpful to consider working with bereaved parents to support the process of adjustment whilst this is destabilised and then to come to terms with their new roles.

Going beyond this meta-ethnography to look further at the impact of perinatal loss, it is apparent that there is growing literature exploring the impact of previous perinatal loss on subsequent pregnancies, but very little research explores the period following a subsequent birth. The literature supports the meta-ethnography in showing that the decision to become pregnant again following a perinatal loss often causes conflicting emotions, including doubt and ambivalence (Cote-Arsenault & Marshall, 2000). Studies reveal that despite these conflicting emotions, around 50%-60% of women become pregnant again within the first year following the perinatal loss (Armstrong & Hutti, 1998; Estok & Lehman, 1983; Robertson & Kavanaugh, 1998). Research looking at the impact of loss on future pregnancies has increased in recent years and again, concurs that perinatal loss causes increased anxiety and depression during future pregnancies (Hunter et al., 2017). A study by Armstrong and Hutti (1998) revealed lower levels of prenatal attachment in mothers who had experienced perinatal loss compared to primiparous women. Lamb conducted a literature search in 2002 looking at the impact of perinatal loss on subsequent pregnancies and parenting. She found

that becoming pregnant soon after perinatal loss could cause unresolved grief issues, which could go on to impact parenting the subsequent child. Similarly, to the current meta-ethnography, she found that anxiety and increased symptoms of depression during pregnancy following perinatal loss were highly documented. She discussed the notions of ‘replacement child syndrome’ which has been used to term when parents use another pregnancy and subsequent child as a substitute for the child they have lost (Robertson & Kavanaugh, 1998) and ‘vulnerable child syndrome’ which refers to parents being overprotective of their subsequent child (Davis et al., 1989). However, she noted that very little research had been done to explore these terms and that these terms were developed in the context of death, without specific reference to perinatal loss (Robertson & Kavanaugh, 1998). She concluded that whilst research has studied the impact of perinatal loss on previous pregnancies, very few studies look beyond this at parenting behaviours with subsequent children. A later study by Warland et al. (2011) looked at bereaved parents’ experiences of parenting children subsequent to baby loss. They found parents adopted a ‘paradoxical’ parenting style as they found parents used opposed and unsustainable ways of parenting. For example, parents would simultaneously feel the need to keep their child close and also maintain distance due to a fear that their child might die. They found that parents described the need to stay in control to avoid a further child loss whilst also describing feeling out of control. They described parents as losing confidence in decision-making, whilst also reporting feeling empowered to make other decisions and similarly experiencing conflict regarding checking on their children versus not checking. The researchers used a thematic analysis which may fail to show heterogeneity in parental experiences. Furthermore, the study included 10 mothers and 3 fathers, so it feels that the voice of fathers and partners is still missing in the literature. The current research aims to address this gap in the literature and build on findings to uncover a more in-depth understanding of couple’s experiences of parenting after baby loss.

A baby born subsequent to a perinatal loss has been termed a 'rainbow baby' by members of the baby loss community (Tommy's, 2023). The symbol of a rainbow suggests that they are a miracle following a storm, a gift to be celebrated. This label may discount or invalidate unresolved grief or conflicting emotions felt by parents. One study looking into the impact of parenting a 'rainbow baby' showed that women with a history of late pregnancy loss showed more negative emotions following the birth of a subsequent child and viewed their baby's routines more negatively than mothers who had not experienced prior perinatal loss (Hunfeld et al., 1997).

Only one qualitative study could be found looking at the impact of perinatal loss following the birth of a subsequent live-born child (Campbell-Jackson et al., 2014). This study collected data from 7 couples using semi-structured interviews, each person was interviewed individually. They explored the impact of prior perinatal loss on subsequent pregnancy planning, pregnancy and following the birth of the subsequent child. Results revealed some difficulties in early attachment with the subsequent child and mixed feelings of joy and guilt following the birth due to unresolved grief. The study mentions briefly that parents viewed their live-born child positively, in contrast to Hunfeld et al. (1997) who viewed their child's routines and behaviours as more difficult compared to their previous lost child. However, parenting of and their relationship with the subsequent child were not explored in depth. They suggested more support may be needed and that attachment difficulties should be normalised following perinatal loss. The current proposed research aims to explore this further with in-depth semi-structured interviews focusing on the period following the birth of the subsequent child up until pre-adolescence. Research suggests that interviewing couples jointly may be advisable when exploring family dynamics, this can increase pragmatic validity as parents do not only exist within a dyadic relationship with them and their child. Interviewing couples jointly can also provide richer data as observations

can be made by the researcher within the interview and the parents can develop their understanding of family dynamics as they explore the questions together within the interview (Taylor & de Vocht, 2011).

1.3.4 Conclusion

Despite its limitations, the current literature review highlights the need for further, more rigorous research on the impact of perinatal loss on both mothers and partners following the birth of a subsequent, live-born child. Future research must consider the longer-term impacts of perinatal loss on the continued family as a whole. One helpful direction would be research on reducing the disenfranchised nature of grief following perinatal loss for parents, especially fathers. Addressing the wider discourse of perinatal loss as unacknowledged may allow families to receive more meaningful care from not only family and friends but also the healthcare system. There is a clear need for further work to be done to update healthcare and service policies and provisions to meet *both* parents' needs following perinatal loss.

Storytelling is a natural way of communicating and sharing our experiences with others. Narrative inquiry allows research to reveal in-depth accounts of individuals' experiences and their perspectives of certain events through the use of a story (Keats, 2009). Narrative inquiry can give voice to populations whose perspective is not often sought or is generally under-represented. It feels particularly appropriate for the current research given that perinatal loss is largely a form of disenfranchised grief and so parents are not always able to share their stories as freely as others would following a different, more socially recognised form of loss, such as losing a grandparent. Parents may find that when they have a subsequent, live-born child, they are further silenced from telling their story of loss due to a perceived societal pressure to be grateful for their 'rainbow baby'.

1.4 Aims and Objectives

The proposed research aims to consider the impact of prior perinatal loss on subsequent parenting by drawing upon the experiences and perspectives of parents as a couple.

The objectives of this study are

- To explore how couples raise a child in the context of prior perinatal loss
- To situate fathers and partners within the narrative of perinatal loss literature

It is hoped that these objectives may provide insight into whether additional support is required and what type of support may be helpful.

2 Method Chapter

2.1 Chapter Overview

This chapter will begin by considering the philosophical and theoretical underpinnings of this research, including my own stance, as the researcher. It will go on to describe the full procedure of the research, from participant recruitment to analysis and dissemination. It will include consideration of methodological rigour and ethical concerns.

2.2 Research Paradigm

2.2.1 Personal reflexivity

I am a Trainee Clinical Psychologist with an interest in attachment, trauma and disenfranchised grief. I, myself, am a rainbow baby. My parents had a baby girl a year and a half prior to my birth. She was born with a rare genetic condition and died at 12 days old. My parents have always spoken about her, and she very much feels a part of our family narrative. My parents did well to conceal their grief and protect me from any anxiety or sadness they were experiencing. However, I still grew up with a sense that something was missing. I often felt myself comparing myself to a sister I never got to meet – what would she have done now? Would she have been better in school? I was often sad that I didn't have my sister to play with but felt my sadness was misplaced, after all, this is someone that I never got to meet. Well into my journey into clinical psychology, I discovered the term 'disenfranchised grief'. This is a form of grief that is not generally accepted or acknowledged by society. I found this an interesting concept and it made sense in the context I learned about it. For example, a mother grieving a son who has been sent to prison for a terrible crime. Of course, the mother must grieve but this is not wholly accepted by society. I thought about it in terms of parents grieving following a miscarriage. This is becoming more accepted by society but is still largely unspoken about and not treated in the same way as one would be treated following the loss of any other relative. Then, one evening, it clicked, my sadness at the loss of my sister was grief, it was disenfranchised grief. I felt an odd sense of relief that this was in fact, an existing term, it felt somehow that this had given me permission to be sad and grieve, despite having never met my sister.

I started to think about how other rainbow babies and their parents had grown to understand and accept the loss of a close family member that they too may never have had the opportunity to meet.

Due to this meeting of personal context to my academic research, I have chosen to write in both the third person, using the conventional language of academic writing, and the first person, to be authentically personal for readers. I have thought about language throughout to decide where I feel academic or personal language is best suited. I have also considered whether to use the language of baby ‘loss’ or ‘death’. Through speaking with parents in my personal life and in my clinical work and with volunteers at Sands, the term ‘baby loss’ was generally preferred. As I am keen to keep parents and families at the centre of my research, I will predominantly use the term ‘baby loss’. However, I have used ‘death’ at times when it contextually makes more sense. Similarly, I have used the terms ‘baby loss’ and ‘perinatal loss’ interchangeably throughout.

2.2.2 Rationale for Qualitative Methodology

Generally, qualitative approaches allow researchers to study the ways individuals navigate and negotiate their experiences, whilst quantitative research aims to understand the relationship between prescribed concepts (Marshall & Rossman, 1999). Qualitative research gives way to the exploration of personal experience, allowing curiosity and expression of individual stories (Denzin & Lincoln, 2018; Sutton, 1993). Therefore, in order to explore the experiences of couples parenting a pre-adolescent child following perinatal loss, a qualitative approach was fitting.

There are various ontological and epistemological positions held within qualitative research (Willig, 2012). This means many different specific methodologies have developed

within the paradigm. I will explore different methodologies to find the best fit for the current research aims and objectives and my own philosophical positioning.

2.2.3 Ontology

Ontology is the position we take in understanding ‘reality’ (Guba & Lincoln, 1982). It is important to acknowledge and explain the researcher’s ontological and epistemological stance as this influences the research methodology (Killam, 2013; Guba & Lincoln, 1994). The methodology is the general approach taken towards the research. The researcher’s ontological position is of a critical realist stance. There is a spectrum of positions one can ascribe to when it comes to ontology. On one end of this spectrum is realism, which asserts that reality exists independent of our conceptual thought (Fletcher, 1996; Lehe, 1998). Therefore, it is assumed that an absolute truth of reality can be found. On the other end of the spectrum is relativism. A relativist position believes that reality only exists in co-existence with an individual’s thoughts or perceptions and therefore there is no absolute truth (Fletcher, 1996). A critical realist perspective understands that an independent reality exists but does not commit to an absolute understanding of that reality. Instead, a critical realist understands that multiple realities may exist based on people’s experiences and perceptions of these (Killam, 2013).

2.2.4 Epistemology

Epistemology is the philosophy of how knowledge is gained; “the study of the nature of knowledge and the methods for obtaining it” (Burr, 2003, p.202; Sprague, 2010). How we make sense of the world and how we acquire knowledge is often unacknowledged and implicit (Willig, 2012). For this reason, Willig (2012) proposes a useful framework for

considering one's own philosophical positioning. She suggests that before beginning research, one must ask oneself the following questions.

- 1) *What kind of knowledge do I aim to create?*
- 2) *What are the assumptions that I make about the (material, social, and psychological) world(s)?*
- 3) *How do I conceptualise the role of the researcher in the research process?
What is the relationship between myself and the knowledge that I generate?*

I took time to reflect on and answer these questions for myself to understand my own assumptions and decipher my epistemological position. When thinking about what kind of knowledge I aim to create, I aim to explore and understand people's experiences. I understand that these experiences may not be reflective of all people's experiences, even if considering the same phenomena. I therefore feel that there are multiple realities or understandings of each experience to be explored. I do think that there is use in considering how individuals choose to construct and relay their realities as this may add a new layer to understanding their experiences.

I believe that people are active in how they construct their realities. I believe that people have multiple selves, and these representations are dynamic over time due to the experiences they have and depending on the sociocultural context they are in. I believe that people's thoughts, perceptions, and feelings of their experiences reflect their own, felt reality.

I view the researcher as having an active role in the research process. I believe that how the participant views the researcher and the researcher's presence in interviews will influence the participant's responses and therefore the data collected. I also believe that the

researcher's own background, context and biases will influence how the data is analysed and thus impact the outcome of the research and the knowledge generated.

By engaging in this reflexive process, I believe a social constructionist framework best fits my personal standpoint and I will therefore let this guide my research approach. This stance guides how I conduct the interviews, how I transcribe the interviews and how I analyse the data. The method, or specific research technique, I am choosing to use is in line with this positioning. This research sits within a social constructionist paradigm, exploring the unique experience of parents parenting a pre-adolescent child following perinatal loss.

Puig et al. (2008) write that the terms social constructionism and social constructivism are often used interchangeably. However, they point out that Schwandt (2001) clarifies their differentiation as constructivism posits that knowledge is gained through self-constructs and constructionism sees knowledge as constructed through conversation and social interaction. As I will be researching couples' experiences of subsequent parenting after baby loss, constructionism is fitting. I believe parents' stories will develop as a couple, as a family and in relation to the wider social world in which they exist. This is aligned with my view of the researcher as an active participant in the construction of participants' stories.

Social constructionism is well suited to the current research topic as it highlights the importance of understanding individuals' experiences within the broader socio-cultural context. This is important as cultural factors and wider societal discourses will affect how individuals grieve and how individuals parent their children. For example, the research has been conducted within a cultural context where grief from perinatal loss is often seen as disenfranchised. This will affect how parents construct and make meaning of their experiences. It is also important to consider how the wider societal pressures and demands placed on parents may influence the construction of their stories. Social constructionism

encourages the researcher to consider how social norms, cultural beliefs, and societal practices influence couples' experiences and decisions. It allows for an exploration of how societal discourses surrounding grief, parenthood, and family influence couples' perceptions of themselves and their parenting roles.

Social constructionism highlights the importance of social interactions and relationships in shaping individuals' experiences and identities. In the context of couples' experiences of perinatal loss, social constructionism enables the researcher to explore how couples negotiate and make sense of their grief and roles as parents within the dyadic relationship. It allows for an exploration of how couples' shared meanings and narratives about their loss and parenting evolve through communication and interaction over time. It also gives space to recognise the power dynamics inherent in storytelling and the ways in which narratives are co-constructed within social and cultural contexts.

2.2.5 Narrative Inquiry

Narrative approaches have become more popular in recent decades since a shift away from quantitative positivist psychology, towards acknowledging the importance of language and subjective lived experience (Murray, 2003). The definition of a narrative is debated amongst researchers (Riessman, 1993). One definition states that a narrative is 'an organised interpretation of a sequence of events [which] involves attributing agency to the characters in the narrative and inferring causal links between the events' (Murray, 2003, p.113). Murray (2003) also suggests that narratives give us the opportunity to define our identity and provide autonomy in the way we choose to convey ourselves to others. Some narrative researchers assert that narratives are essential in processing and making sense of our experiences, ourselves and our world (Murray, 2003; Sarbin, 1986). Ricoeur (1984) states that narratives are constructed logically to transform sequences into meaningful plots and that humans need

these to bring order to an ever-changing world. Bruner (1990) builds on this idea that we need narratives to make meaning by showing that the need for organization and coherence increases when life appears disorganised and incoherent, when there are conflicts between the self and society or between ideal experiences and reality. Such events may include illness, bereavement, or divorce. Bruner argues that it is at these difficult times that people often construct and tell narratives. It is argued that this process helps to make sense of the events and gives them meaning by creating order and taking control (Rimmon-Kenan, 2002). This meaning-making process makes difficult events more manageable to process. It is therefore argued that some narratives can have a therapeutic function. In therapy, a narrative approach seeks to identify the harmful stories people construct of themselves and the world around them and supports them to reconstruct new stories that are more helpful to them (White & Epston, 1990). Narratives can allow individuals to reconstruct their understanding of their reality and their identity to shine a more positive light on their experiences.

Regardless of the exact method of analysis, narrative analysis must be systematic, clear, and provide insight into the structure of the narrative, its functions and its social or psychological implications (Josselson & Hammack, 2021). A narrative approach would be helpful for the current research as it can uncover unique perspectives and inform a richer understanding of a situation as told by the narrator. Using a social constructionist lens, knowledge is not a possession, but something that can be jointly created through the construction of language (Gergen, 1985). Grounding narrative analysis in social constructionism would allow exploration and interpretation of the couple's story as a whole and how they are representing and parenting their living child in the context of a prior, perinatal loss.

A further advantage of using narrative analysis for the current research is the flexibility in its approach to data analysis so this can be tailored to the research aims.

Narrative analysis aligns with my own philosophical views that knowledge is based on human experiences and then socially constructed. This fits well with using storytelling to better understand couples' experiences of baby loss. It is also documented that narrative analysis is useful in giving voice to groups that are often unheard which fits well with the research objective to bring fathers into perinatal literature.

Furthermore, it is assumed that narratives are expressed sequentially and provide meaningful, temporal information (Squire, 2008). As the systemic review of the literature showed, the impact of perinatal loss is temporal and dynamic over time. Narrative analysis would be able to capture this.

Narrative analysis also allows consideration of the wider context of the stories told, including the influence of society on the narrators (Esin et al., 2014; Riessman, 2008). Baddeley and Singer (2010) write that narratives are influenced by the wider contexts of culture, history and societal discourses. This compliments my personal stance as a researcher, as I do not believe stories can, or should, be constructed in a way that is void of their context. Given the aims and objectives of the current research, other types of analysis will be considered in order to ensure the best approach is being taken.

Thematic analysis has only been considered a method in its own right somewhat recently as some researchers view it as a skill used across a range of methods of analysis for qualitative data (Ryan & Bernard, 2000). Thematic analysis is a method for identifying and organising patterns in content and meaning within qualitative data. Thematic analysts will look at data, find common threads of meaning, group these into categories and then cluster these into higher-order themes. Due to the method's popularity, there are multiple sources of comprehensive guidance on how to conduct a high quality thematic analysis. Braun and Clark's (2021) six-step guide to conducting a thematic analysis is amongst the most popular. They inform researchers that thematic analysis (TA) is not linked to a specific

epistemological position (Braun & Clark, 2021). It is therefore up to the researcher to decipher their own philosophical stance and decipher the meaning of the themes identified based on this.

The advantage of using TA would be the abundance of clear guidance on how to conduct this method of analysis. This would be advantageous as a novice researcher to ensure a quality analysis of data is conducted. The freedom of theoretical standpoint is also useful as the research can be tailored to the researcher's own positioning. However, a narrative approach appears in keeping with not only the aims of the current research but also with my stance as not only a researcher but also as a clinician and thus will be the chosen methodology for this research.

2.3 Participants

2.3.1 Parents' Voices

During the initial stages of the research project, prior to seeking ethical approval, the researcher constructed the research materials alongside the research proposal. The research materials included a recruitment flyer, the participant information sheet, the signposting information sheet, the pre-interview questionnaire and the interview guide. To ensure that parents' voices are embedded throughout the research and that all components of the research are aligned to their perspectives and worded sensitively, parents with lived experience of perinatal loss were asked to review the materials. This was done via the Sands research support team. The research officer at Sands spoke with a number of parents who had identified themselves as being interested in helping with or participating in research in the area of perinatal loss. These parents were given a brief outline of the current research project and given the researcher's contact details should they wish to help in reviewing materials. In the following weeks, three parents with lived experience of perinatal loss contacted the researcher via email and confirmed they would be happy to review the research materials.

Following feedback and corrections from these parents, the materials were amended, finalised, and submitted for review by the ethics committee.

2.3.2 Inclusion Criteria

Participants are parents who have gone on to have a surviving child born after experiencing a perinatal loss. For the purpose of this research, perinatal loss was defined as the loss of a baby at any time during pregnancy or within the first 28 days of life. Perinatal literature breaks perinatal loss down into different periods. Miscarriage can be defined as an early baby loss, under 24 weeks gestation. Stillbirth is a baby loss during pregnancy but beyond 24 weeks gestation. A neonatal baby loss occurs within the first 28 days of life. It felt important not to limit participation by type of loss, or stage of pregnancy, as baby loss at any stage can have a huge impact on parents. For the purpose of this study, I have used the terms ‘perinatal loss’ and ‘baby loss’ interchangeably.

The subsequent, surviving child needed to be above the age of one to ensure enough time had passed since the prior perinatal loss. Originally, an inclusion criterion of the subsequent child being pre-adolescent was to be stipulated to limit difficulties with recall. However, after speaking to parents with lived experience, those who felt their parenting had been impacted by previous perinatal loss were able to clearly recall this. Therefore, this criterion was removed. Instead, the inclusion criteria were updated so that there was no upper age limit for the subsequent, surviving child. Instead, parents were asked if at least one parent within the couple felt their parenting was impacted by prior perinatal loss and whether they felt able to recall how this was in the years that their subsequent child was pre-adolescent. If this was the case, they were able to be included in the research. Inclusion criteria also stipulated that participants must be willing to be interviewed as a couple. Both heterosexual and same sex couples were able to participate.

2.3.3 Recruitment

Purposive sampling was used as participants were selected based on their experiences. Participants were recruited via relevant charity organisations in the UK, such as Sands posting on their social media. A recruitment flyer was provided by the lead researcher, however this was not then used (see Appendix B). The social media post contained the lead researchers' contact details so that potential participants could get in touch to find out more about the research and whether they were eligible to participate. This allowed potential participants to ask questions before agreeing to participate in the study.

The lead researcher contacted various other support organisations, however this was of varying success. It was hoped that if online forums were able to share the recruitment flyer, then further recruitment may have occurred via the 'snowball technique'. The lead researcher received consultation from NHS organisations regarding recruitment, however, did not recruit via these organisations as this would have required additional ethical approval that would not have been feasible within the timeframe of this research.

Predicted difficulties during recruitment were due to the emotional nature of the topic being explored and difficulty finding participants who have experienced both perinatal loss and have had a subsequent child over the age of one. It was predicted that these participants may be difficult to access as they were unlikely to still be accessing support services at the time of recruitment. As the eligibility criteria require parents with a subsequent child over the age of one, unless they have had another, more recent child, they will no longer be under the care of perinatal services.

Some potential participants contacted the lead researcher keen to take part but reported that their partner did not want to participate in any research. This made them

ineligible for participation but also raised an interesting point for later discussion, that partners were unwilling to participate in research. It was most commonly the male partner who was unwilling to participate in the research.

There does not appear to be a consensus on how to determine sample size prior to commencing qualitative research (Mocanasu, 2020). According to Emerson and Frosh (2004), narrative analysis involves the detailed exploration of a very small number of subjects, whose narratives are of individual interest, rather than a source for generalisation. Bryan and Loewenthal (2007) took a case study approach to narrative analysis, they used Gestalt principles and focused on ensuring coherence of the narratives. As the current research follows a social constructionist epistemology within critical realist ontology, it posits that knowledge is made up of unique, dynamic experiences understood through the lens of the narrator who is influenced by their past and personal constructs. Therefore, participants' stories and experiences are unique constructions, and all will be transferable in some way as shared human experiences will overlap. A large sample size is not necessary as the aim of the research is not to establish a 'truth', but rather to gather enough stories that they will be relatable to others with similar experiences.

Recruitment was done in two phases, the first in October 2022 and the second in April 2023. Once participants were deemed eligible, they were provided with a Participant Information Sheet (see Appendix C). Following reading this and asking any questions they may have had, participants were required to provide written, informed consent before taking part (see Appendix D). A total of 81 couples came forward, but not all met the inclusion criteria and not all followed up after receiving further information about the study. A total of 15 couples, and therefore 30 participants in total were recruited and included in the final analysis.

2.4 Data Collection

Once written, informed consent had been provided by participants, they were sent signposting information in case they required further support and a pre-interview questionnaire (see Appendices E and F). The questionnaire asked participants for demographic information such as their name, age, gender, ethnicity, and disability status (see Table 1). The questionnaire also asked about their perinatal loss or losses, when this occurred, the current age of their rainbow child and if they have any other children. This also asked how parents would like their children to be referred to within the interview. This was to ensure the interview was person-centred and to avoid causing distress. Upon completion of the pre-interview questionnaire, interviews were arranged with the participants. Scheduling was done via email and phone calls, depending on the participant's preference.

Table 4*Research Sample Demographics*

Demographic		Frequency
Age	30-39 years	12
	40-49 years	15
	50-59 years	1
	60-69 years	2
Disability	Yes	0
	No	30
Relationship status	Married /Cohabiting	30
	Divorced /Separated	0
Ethnicity	White: British	23
	White: European	2
	White: African	2
	Asian	1
	White: Scottish	2

2.4.1 Narrative Interviews

The research interviews were conducted online via Zoom, using video calls. This was done to aid access to participation as there was no need to consider childcare or transport to a location for the interviews. This should also have increased couples' comfortability as they are likely to have been in their own homes, meaning they were able to speak freely and interact with each other more naturally. Gray et al. (2020) found that participants felt more

comfortable talking about personal topics, such as parenting, when they were in a space of their own choosing using online video conferencing. Prior to commencing each interview, participants were asked if they were in a private space. This was important to ensure responses were not limited due to parents feeling overheard by their children or others.

According to Sohier (1995), dyadic interviews can provide a co-constructed reality between two participants who have experienced a similar or the same event. They can reveal more detail than individual interviews as individuals can prompt each other and fill in where the other may miss or discard some information. Sohier (1995) suggests that from a systems perspective, different accounts of events are necessary to provide the researcher with a fuller, co-constructed understanding of what happened. Joint interviews in the context of couples allow couples to make sense of their experiences together as they can convey meaning to somebody else with whom they have shared the experience, rather than just themselves (Mattingly, 1998).

Couples were therefore interviewed jointly, at the same time, to provide a richer, more detailed account of their experiences of parenting a child born subsequent to baby loss. A parent's grief and their relationship with their subsequent child or children does not exist in isolation. Depending on their familial setting and cultural context, different factors may influence them. Interviewing couples jointly brings a part of this context into the data collected. Joint interviews enable relational and interactive aspects of participants' experiences to be showcased through shared storytelling (Bjørnholt & Farstad, 2014; Radcliffe et al., 2013). Holstein and Gubrium (1995) suggest that if a partner is likely to be spoken about in an interview, this suggests they are a part of the narrative and should be included in the interview. This is relevant when exploring parents' experiences of raising a

child as they are not parenting in isolation. It is recognised that this is not reflective of all familial settings but is the focus of the current research.

Narrative interviews can adopt various approaches. Brinkman and Kvale (2015) suggest that a narrative interview can start with a question about a specific episode, period or theme or ask for a life story. They then suggest that after this initial question, the main role of the interviewer is to remain a listener, avoiding interrupting the interviewee. They suggest that through follow-up questions, nods or even silences, the interviewer is a co-producer in the narrative. Riessman (1993) suggested some techniques to elicit more detail from narrators or support them if they became ‘stuck’. Techniques included the interviewer reflecting some of the interviewee’s words back to them or using probe questions. Riessman (2005) stated that narrative interviews are conversations in which meaning is co-created. Therefore, narrative interviews must allow freedom for flexibility of both interviewees and the interviewer. A rigid, structured interview would not be appropriate within the context of narrative inquiry (NI). An interview guide was therefore used to ensure interviews were eliciting narratives of similar, relevant topics but the included prompt questions did not overly constrict participants in constructing their narratives (see Appendix G). The same initial prompt question was used in each interview: “Are you able to describe how you feel the loss of your baby/babies **name(s)** has influenced your parenting of **rainbow baby/babies name(s)**?”

However, in order to keep the interviews more conversational and to avoid limiting the construction of participants’ narratives, follow-up prompt questions and interviewer responses varied. Due to the social constructionist epistemology of this research, this variation in interviewer input does not invalidate the results.

With informed consent, all interviews were recorded and transcribed to negate the limitations of researcher recall and ensure the data analysis was conducted directly from participant data. Transcription was completed solely by the researcher. The level of transcription required varies depending on the research aims and the type of analysis being used. For narrative analysis, it was deemed appropriate to transcribe only the content of the interviews, including researcher questions and participant responses. It is not viewed as necessary to include details such as pauses or to annotate where participants or the researcher may have made non-verbal communication with facial expressions or body language or changes in intonation (Crossley, 2000). However, it was important that transcripts were detailed and verbatim (Halcomb & Davidson, 2006; Smith, 2016). An example transcript is included in Appendix H.

2.5 Data Analysis

Due to the growing popularity of NI, there are now a wide variety of approaches to interpreting and analysing narratives (Hiles and Cermak, 2008). Contrary to some forms of qualitative analysis, there are no set procedures or protocols for analysing narratives (Riessman, 1993; Squire, 2008). Mishler (1999) suggested that narrative analysts should consider what can be gained from different approaches of analysis prior to committing to a specific method of narrative analysis. This choice must also consider the researcher's theoretical stance and the aim of the research. Therefore, different approaches to narrative analysis are explored below.

Atkinson (2006, 2010) takes a hyper orthodox approach to narrative inquiry in which he attempts to rigorously analyse stories and maintain objectivity to the narrator. Frank (2010), on the other hand, considers the stance of the storyteller and views the researcher as an empathic listener. It is argued that a hyper orthodox approach takes away from the

richness of narrative inquiry and trying to organise narratives into systems developed for positivist science would not be of use to the storytellers and detract from the clinical utility of the research (Bochner & Riggs, 2014). As a researcher and a clinician, I feel it is important that the end product of my findings is useful to the storytellers who contributed to the data. Therefore, I have chosen to take a caring stance to the storytellers, rather than standing apart for the purpose of objectivity (Bochner, 2010). In line with this, Bochner (2012) discusses stepping away from academic writing and relaying stories containing emotions that bring the participants to the forefront and give life to their narratives. Given the emotional nature of the topic I am researching, this feels appropriate in conveying the findings.

In considering the process of narrative analysis, one way of using NI is a thematic narrative analysis (Bengtsson & Anderson, 2020). This is deemed the most simplistic approach to NI. This method focuses on the content of narratives, with little consideration for the influence of the context in which they are told (Riessman, 2008). Other methods focusing on the content of narratives are described by Squire et al. (2013) as taking an event-centred (Labov, 1972), or an experience-centred approach (Ricoeur, 1984). Both approaches posit that narratives allow “individual, internal representations of events, thoughts and feelings” to be externally expressed (Squire et al., 2013, p.5). However, an event-centred approach assumes stability in these representations and an experience-centred approach assumes that these representations are dynamic over time and across contexts. This area of NI had been broadly defined as the ‘what’s’ of a narrative (Smith & Sparkes, 2009). Given the current understanding in the literature of the impact of baby loss as changing over time, I will be regarding stories as dynamic and subject to change.

Alternatively, another method of NI, broadly defined as the ‘how’s’ of a narrative, considers the social construction of narratives (Smith & Sparkes, 2009). This approach posits

that narratives are not representations of internal states, but social acts formed through dialogue (Squire et al., 2013). Riessman (2008) refers to this approach as a 'performance analysis' which is varied and interpretive, allowing the researcher the flexibility to make choices. This type of analysis pays particular attention to the language and structure of narratives and allows researchers to explore how the stories are developed intersubjectively through dialogue. It considers how social identities are performed and therefore formed, and how they evolve, become restrained by, or resist societal and cultural influences. This can be helpful in considering contextual influences on narratives and uncovering subconscious ideas.

I will be integrating these approaches in order to consider both the content and the co-construction of narratives. In a critical review, Riessman and Quinney (2005) gave examples of what they believe to be well-executed narrative research. They expressed a preference for narrative analysis that comments on the language and structure used, the context and dialogic nature of the storytelling, and the use of a comparative approach. The latter referring to commenting on similarities and differences among the participant's stories. I will be using this integrative approach to narrative analysis to better understand couple's experiences of parenting in the context of prior perinatal loss, whilst considering the situational context of the research interview and the wider societal context. I believe both aspects of the couple's narratives will be important and helpful in understanding the stories shared. The current study focuses on the relational experiences of parents to their children and their losses by the stories they tell as a couple. Performance analysis allows the researcher to delve into the stories, whilst considering their context alongside societal and cultural influences. This can include reflexively considering my role as the researcher and as a rainbow baby, in the co-construction of the stories told by parents as I re-tell and interpret these. Of equal importance will be the content of the stories they share, considering the events described in the stories

and what these illustrate in relation to understanding more about couple's experiences of parenting in the context of prior perinatal loss.

Fraser (2004) offers a seven-step guide to narrative analysis, but also recognises that there is no one way of approaching this. Fraser (2004) suggests a process of hearing the story and experiencing the emotions, transcribing the narratives, and then interpreting each story individually. I used this as a guide to analysis as I transcribed each interview and read each one through to consider it as a whole story. I then went through each transcript by hand, highlighting all elements of each story that felt important according to the influences of Riesman (2008), such as performance, content, and context. I then transferred each of these interpretations onto an Excel spreadsheet and colour coded them to begin to use a comparative approach, looking at similarities and differences in each story. Throughout each stage of analysis, and the final write up, I will hold closely the influences of Frank (2010) and Riesman (2008). These influences will be woven throughout each step of the process as the stances I am drawn to will naturally impact how I hear each story and how I experience the emotions. I will keep a reflective journal to aid the process of experiencing the emotions and considering the context of each interview. An example of my method of analysis as applied to a section of a transcript is included in Appendix I.

2.5.1 Methodological Rigour

Whilst quantitative research may consider generalisability in examining rigour, it is deemed more helpful to consider transferability within qualitative research. Transferability refers to the extent to which a studies results can be applied to other contexts. There is little guidance on how to ascertain the quality of narrative research and this is a continuing debate amongst researchers. Clandinin and Connelly (2000) focused on verisimilitude and transferability as markers of quality assessment, however, they did not elaborate on how to

assess for these. One indicator of transferability may be the sample size. A larger sample size was used in this research as compared to most research study's using narrative inquiry. However, the chosen approach of performative/dialogic narrative analysis means that the aim of this study is not to presume transferability, but instead to hear the voices of a small group of parents that have had a particular experience. Narrative researchers do not use certain language and do not aim to present universal facts, but instead present ideas to their reader (Borland, 1991). McLeod and Lynch (2000) suggest that the goal of this kind of research is to show a part of social reality that enhances understanding and contributes to new ways of seeing that reality, rather than finding an explicit explanation of a phenomenon.

The subjectivity of participants' stories is considered acceptable in narrative inquiry as it is how life is experienced that has value and therefore traditional views of methodological rigour must be redefined (Bochner & Riggs, 2014). Subjectivity in narrative research can be seen as a strength as I have made it clear that I do not aim to find a 'truth' in this research, but rather to uncover 'narrative truths', as worded by Spence (1984). As Riessman (1993) suggests, stories of the same event can be told in many different ways and stories of complex experiences should vary as they are selective reconstructions. Narratives are situated in and affected by social discourses and power relations and rather than viewing these as limitations as traditional notions of reliability may suggest, these should be reflected on and considered alongside the findings (Mishler, 1990; Riessman, 1993).

Levitt et al. (2021) discuss methodological integrity, rather than rigour and stipulate that a core component of this is assessing the utility of the research. They define utility as how effectively the study produces findings relevant to its goals. They posit that the research method, design and procedure should all align with the specific aims of the study. I have outlined my decision-making at each stage of the research process and this has been done with the research aims in mind. Levitt et al. (2021) state that the utility can be strengthened

by the researcher actively engaging in a reflective process regarding their epistemological positioning so that this can be considered alongside the research aims when choosing the method. Similarly, to determine the quality of narrative research in particular, Polkinghorne (2007) suggests that the researcher must justify their chosen method and explain what kind of knowledge they aim to create. I have expressed this in explaining my reasoning for choosing narrative analysis and by clearly stating my ontological and epistemological positioning. Polkinghorne (2007) also suggests that narrative researchers must recognise the threats to the validity of their research to produce valuable results. I have explored the limitations of the current research in detail in the discussion chapter. According to these criteria, the study is of good quality and utility.

It is also important to consider the role of the researcher when interpreting research. Within narrative research, it is understood that the researcher plays an active role. Their presence and the questions they ask during interviews impact how participants tell their stories. The analysis of this data is then also affected by the researcher's own background, context, beliefs, and biases. To account for this, I will be continually engaging in a process of reflexivity and making this known to the reader. The perspectival nature of narrative research is known and viewed as a feature of narrative research, rather than as problematic.

Riessman (1993) suggests four ways of approaching validation in narrative work; persuasiveness, correspondence, coherence, and pragmatic use. She writes that persuasiveness is richest when findings are clearly supported by evidence from the data, or narrators' stories, and says that persuasiveness can be enhanced by the consideration of alternative interpretations of the data. Correspondence refers to the process of taking findings back to the participants to check they adequately reflect their experiences. Due to the limitations in timing, checking findings with participants was not possible in this research. However, the final findings will be shared with all participants and Blackman (1992) states

that this can be useful in continuing meaningful dialogue around the research area after the formal research process itself. Riessman (1993) refers to three levels in which coherence should be sought and these three levels were stipulated by Agar and Hobbs (1982). The first level is global which refers to the narrators' overall goals in speaking. Secondly, local refers to how the narrators link their story together. Thirdly, themal refers to the recurring themes that occur during a person's spoken word. They suggest that the interpretation of data is strengthened if the data can be understood in terms of all three levels. As rich, in-depth interviews were conducted with each participating couple, all three levels could be seen and considered in the interpretation of each story. Lastly, pragmatic use refers to the extent to which others may use the findings as a basis for further work. Mishler (1990) agrees that if others believe the study to be trustworthy then they may use the findings as a foundation and reference point for further work. This criterion is future-oriented and difficult to consider at the time of writing the research. However, Riessman (1993) suggests researchers can increase the likelihood of their work being viewed as trustworthy by describing how interpretations were made and making primary data available to other researchers.

2.6 Ethical Considerations

Prior to commencing this research, a risk assessment was completed, and ethical approval was gained from the University of Essex ethics committee (see Appendix J).

2.6.1 Participant Wellbeing

Due to the emotionally sensitive nature of the research, it was imperative to consider participant wellbeing throughout the research process. In order to ensure materials were worded sensitively and acceptable to participants, parents with lived experience reviewed all the research materials prior to these being finalised and sent for ethical approval. Parents with lived experience were sourced via the baby loss charity, Sands. These parents contacted the

researcher directly and were asked to review the materials to ensure these felt sensitive, relevant, and containing. These parents were also asked if they would want anything added to the materials that they felt may be missing. This process was very insightful and led to various changes in wording to be more inclusive to parents who may have experienced multiple losses and/or have multiple rainbow babies. Having parents read through the materials helped minimise any potential distress during the participant journey.

To further minimise any potential participant distress, inclusion criteria stipulated that the interview must be conducted at least one year following the couples' most recent baby loss. This was so that parents were further from the event and had more time to grieve and process their loss.

During interviews, the level of participant's distress was considered due to the nature of the topic being explored. It was planned that in conjunction with professional interview etiquette, if any participant presented as highly distressed during an interview, they would be reminded that they are able to stop and withdraw participation at any time or take a break from the interview and resume when they wish. Participants were reminded of this at the start of every interview, however, this was not deemed necessary by any participants.

Some research has shown that interviewing couples jointly can cause tension in the couple's relationship, especially if there is a disagreement in views, or if a partner shares information during the interview that they have not previously shared in front of each other (Bottorff et al., 2005; Gysels et al., 2008). The researcher kept this in mind when conducting interviews and looked out for any signs of distress or discomfort when participants were speaking. The plan was for the researcher to remind participants of their right to take a break at any time, to discontinue the interview at any time or to withdraw their participation from

the study at the point of the interview if high levels of distress were seen. However, once again, this was not necessary in any of the interviews.

It felt important to approach interviews with a curious, non-judgemental stance and make the overall purpose of the interview clear to participants from the start. Written information on the purpose and nature of the research was given to parents before and after participation. Before starting the interviews, parents had an understanding of what to expect and were asked to provide informed, written consent. A benefit of recruiting participants through support organisations is this suggests that participants have accessed support to process their loss. Some existing research exploring experiences of perinatal loss has mentioned that rather than increasing distress, parents were glad to be given the opportunity to talk about their loss (Obst et al, 2020).

Another way of minimising distress during interviews was the careful ordering of the interview guide. The researcher spent some time at the start of each interview on introductions and setting up the interview before beginning with more generalised, less personal questions. This allowed participants to relax and build a rapport with the researcher before being asked to explore an emotive topic. The researcher allowed time at the end of each interview to slow down again and reflect so that participants did not leave the interview feeling uncontained. Being interviewed jointly as a couple was predicted to help minimise distress as participants could support one another if a person did become distressed. This was witnessed in the interviews and appeared to be a helpful factor in mediating distress.

As emotionally sensitive information was explored in the interviews, signposting information to perinatal loss support services was given to all participants in case they wished to seek further support. If any participant presented as highly distressed in the interview, as well as being reminded that they were able to stop and withdraw participation at any time or

take a break from the interview and resume when they wish, it would have also been possible to support them to seek additional support from charitable organisations such as Sands. However, these measures were not needed as couples were able to support one another. The interview process supported Obst et al.'s (2020) findings as all participants gave positive feedback, saying that they had found the process cathartic and felt grateful for the opportunity to share their stories.

2.6.2 Potential Disclosures

A further consideration was that as participants were being interviewed regarding their parenting, there was a potential for child-safeguarding concerns to be raised. If this were to happen, risk would have been explored and escalated as necessary. This issue did not occur in any of the interviews.

2.6.3 Confidentiality, Anonymity, and Data Storage

Interviews were audio recorded and transcribed. All participant data was anonymised at transcription and securely stored. Recordings were deleted as soon as they had been transcribed and transcriptions were deleted once the data had been analysed. This is with the exemption of one example transcript shown in Appendix H.

2.6.4 Researcher Wellbeing

As well as considering the welfare of participants, it was important to note that interviews were conducted alone by the main researcher. Hearing and talking through distressing events with parents with lived experience of perinatal loss carried the potential to be emotionally taxing. This may have been particularly true if participants had a similar story to that of the researcher's parents. It was therefore important for the researcher to continue to

practise self-care, remain reflective and notice when the researcher's own well-being was being impacted. It felt particularly important to keep this in mind during interviews, following interviews and then again during transcription and data analysis. The researcher had two supervisors with the University of Essex and additional supervision from Sands; all of whom were able to provide a safe space to talk through any difficulties experienced by the researcher, in terms of their own wellbeing. Regular supervision meetings throughout the research process ensured this was easily accessible.

2.7 Chapter Summary

This research is framed within a social constructivist paradigm. This carries the assumption that individuals socially and psychologically conceptualise their experiences and thus construct their world. This underlying assumption meant that the research prioritised keeping the participants' narratives at the heart of the study. It was decided that a narrative analysis would be the best fitting methodology for this as it views participants' stories as whole, individual understandings rather than attempting to compare accounts between participants. Fraser's (2004) seven-step approach to narrative analysis was used as a rough guide. Narrative interviews were selected as the main method of data collection to allow couples to share their stories with only a few prompt questions to avoid having too much influence on the construction of their narratives. Once transcribed, the interpretation of the narratives will be influenced by Frank (2010) and Riessman (2008).

3 Results Chapter

3.1 Chapter Overview

In this chapter, I will begin by describing each of the participants, or narrators, to provide a context to their stories. The findings from their stories are then broken down into narrative features and narrative types. The narrative features reflect the more dialogic, performative aspects of the couple's stories, whereas the narrative types are more reflective of the content of the couple's stories. The narrative features are described first as they provide a context to the narrative types that follow.

3.2 Introducing the Narrators

The structure of each couple's family, including the babies they have lost, is detailed in Table 1. This outlines the basic context from which each couple's narrative is performed and introduces the main characters of each story. All information shown is presented as it was written by the participants in the pre interview questionnaire. All included characteristics, such as ages and time since loss, are as described at the time of the interview.

Table 5*Details of Participants Baby Loss and Their Children Born Before and After This*

Couple pseudonyms	Pseudonym of baby(s) that died and stage of loss(es)	Yeas since most recent loss	Pseudonym and age of rainbow baby	Pseudonyms and ages of other children
Carol and John	James, born at 29+4 weeks gestation, and died 3 days after birth	7 years	Elijah, 6	
Anita and Ben	Theo, 16+4 weeks gestation; Little Angel, 10 weeks' gestation	3.5 years	Jacob, 19 months	Sebastian, 9
Jane and Harry	Mason, 37 weeks' gestation	4 years	Logan, 3	Luna, 7 months old
Sharon and Mathias	Twins Elias and Caleb, 31 weeks' gestation	12 years	Emma, 10	Matt, 9, Louise, 7, Ed, 1.
Blake and Edward	Joy, 41+4 weeks gestation	13 years	Daisy, 10	Tabitha, 15, Jamie, 7
Jackie and Arthur	Ivy, 27 weeks' gestation	7 years	Ruby, 5	Mike, 10, Evie, 2
Freya and Ethan	Noah, born at 26 weeks' gestation and died 5 days after birth; multiple prior baby losses including a medical termination at 12	3 years	Lucas, 2.5	

	weeks' gestation and 5 early miscarriages			
Lisa and Sam	Gabriel, 30 weeks' gestation; Bella, full-term	15 years	Hugo, 12	
Erika and Lars	Roman, 16 weeks' gestation; Jessica, born at 23+5 weeks' gestation and died 6 weeks after birth, one miscarriage prior to this	3 years	Twins, Jude and Jackson, 13 months old	
Mia and Arlo	Miscarriage at 4 weeks, twin, Otto, born at 32 weeks' gestation and died at 10 days old	8 years	Twin, Ruben, 8	Derek, age unknown
Madison and Josh	Ciara, 41 weeks' gestation	10 years	Alana, 8	Sian, 14
Daria and George	Miles, 40+1 weeks' gestation	8 years	Seb, 6	Phoebe, 4
Cathy and Isaac	Johnny, died shortly after birth	27 years	Thomas, 26	Two daughters, 33 and 32
Alyssa and Fred	Sofia, at 38 weeks' gestation	8 years	Isabella, 7	Matteo, 6
Vicky and Elijah	Cassius, born at 25+4 weeks' gestation and died 5 days after birth	3 years	Leo, 2	

3.3 Narrative Features

3.3.1 *The Chapter Stays Open*

As all the couples shared their narrative of how they are parenting their children born subsequent to loss, it appeared that the chapter in their lives of baby loss remained open. It seemed they were juggling two storylines. Both appeared to still be unfolding and ongoing. Parents kept their lost babies in mind and considered them in current decision-making for parenting their surviving children.

Parents kept these absent characters present in various ways, by keeping their baby in mind, speaking about their baby, carrying out various rituals on significant dates and engaging in projects relating to baby loss. Keeping the absent character present was a way for parents to preserve their memory and in some ways, keep them alive. Storytelling was an important way of doing this for almost all the parents interviewed. Parents expressed that it was important to them that the absent characters remained a part of the family and were spoken about by their children and others. Therefore, for almost all the couples, the story of their loss is a narrative they freely share with their living children. However, for Jane and Harry, this is a private story that they worry their children will tamper with if told too soon. As a way of preserving her memory, Jane prefers to keep her loss narrative very factual and therefore does not want to adapt this in a way that may be more acceptable to her living child. She is therefore willing to wait until he is of an age where he will be able to understand the story in full. For the most part, parents felt that whilst the absent characters were being spoken about, they were not forgotten and could remain a part of the family. Keeping the chapter of loss open was important to not only preserve the memory but also to allow parents

to maintain and continue to build their relationships with the lost babies. Jane also felt this was important but engaged in other ways of doing this.

All the couples kept physical reminders of the absent characters in various forms, such as photos, keepsakes, Christmas decorations, or objects that had associated meaning to their babies, such as white feathers, octopus' and rainbows. These objects facilitated parents to keep the chapter open by prompting them to think about the absent child, thus fostering conversation about the absent child with others and keeping space for the absent child in their lives and in their homes. At times, keeping and treasuring objects as representations of their baby presented a challenge for parents. For example, Jane has a necklace that reminds her of the baby she lost and helps her to continue to feel close to him, however, if her subsequent children play with the necklace, it feels as though they are interfering with her relationship with the baby they had lost. Similarly, Sharon and Mathias shared a story of when they tried to look over their keepsakes and memories on the anniversary of the baby they lost. They hoped this would be a special time to remember and connect with their baby, however, their surviving children became bored and disruptive, not understanding the meaning of the occasion for their parents, and this was felt as disrespectful to their relationship with the baby they lost. Similarly, other parents described struggling when changes in their homes needed to be made which meant altering or moving objects of significance.

Some parents felt that by keeping the chapter open they were not only able to stay connected but also to continue to develop their relationship with their baby. For example, Alyssa and Fred buy new objects that remind them of the absent child and in this way, keep their relationship as ongoing and developing. Below, Blake and Edward describe how they continue to take opportunities to remember, parent, and build their relationship with Joy.

Edward: And part of that's intentional, right? It's like, you know, I mean, I I I still, I still remember on the day saying to Blake that we were lucky because we didn't have all those memories and all those beautiful moments to make us love her and miss her more. Umm. And we've very, very quickly learned that that was actually totally wrong. And because we didn't have those things, it made it even harder. And I think that's partly why we clutched all these things because we're desperate to... Have everything that we do of her to remember, you know, and it's like like people will ask or say something that'll make us make a comment and then they'll go, Oh my God, I'm sorry.. Like they immediately like ohh crap. I've made them go to a bad place.. where we're like, no, no, no, we want the moments and the opportunities to talk, you know, every time you let us open our mouths and talk about who we're remembering her and, you know, enjoying her life. So yeah.

Blake: And I guess the birthday thing in, you know, to remember her on her birthday. It's also part of being able to mother her. So it's it's, it's when you, it's when you're given an opportunity to Mother her. So I can be her mother on her birthday and get her birthday cake. You know, and sing happy birthday. And for me that's very important because those are the only mothering moments I'm gonna get for her. You know, it's like doing this with you. This for me in my head is I'm giving Joy some attention now. In a way that I can't actually do that, but for me, this is my mothering her. Because as a mother you've got parent teacher meetings and you know, this is my moment to dedicate to Joy, you know. And we definitely do look for any opportunity to have those opportunities to mother her.. father her, you know, Ed decided that we were gonna run the London Marathon last year cause it fell on her birthday.. It was on her birthday. And, you know, he was like it never gonna. It's not always gonna be on the 3rd of October. But it is. We've got to run it, you know. And the training was was gruelling. I mean, Ed's a runner. So, you know, he did amazing. And, you know, he had to wait for me. But, you know, for him it it was something he really wanted to do. I never, ever, ever planned

on running a marathon. But I just had to tell myself that, you know, all the time I put into the training was my time to mother her, you know.

Edward: But again, I mean it, Blake says. Well Ed is a runner, but I wasn't. You know, when, when.. When we lost to Joy I and I decided to do something, you know, the the immediate was.. Well, I'm a cyclist, I could ride my bike. But then I wanted to do something that was really difficult, like losing a child and cause I've always hated running.. That's why I chose it. And I mean, you know, 12 years later, I still run because you know what I realized was in the beginning, I started talking to her.. To distract myself from the pain. And I almost, you know, after, after a couple of months, I learned to love running. And it was, you know, it wasn't so much like that. But I still find. You know. When I get to that place where you sort of.. The runners high, I suppose, when you sort of transcend that and you go into that state where the pain falls away. Instantly, I start chatting to her and you know it's and it's interesting because depending on how I go into that state, sometimes I'm talking to a 12 year old Joy. Sometimes I'm still babying her like it was on the first day. But you know, I go to that place in my head and it's part of what I love about running so much, you know.

– Blake & Edward

Other parents expressed similar feelings, that when they engaged in volunteering or research such as the present study, it provided an opportunity to continue to parent the baby they lost. Parents felt that as they were unable to parent the absent characters in a traditional sense, they were keen to engage in activities that enabled them to dedicate time to their babies and do for them what they could, despite their absence.

A further way of taking opportunities to continue to parent their absent children was for parents to continue to engage in rituals on birthdays and other significant dates for their

children who had died. Rituals included sharing cake with family, buying gifts, family days out and visiting significant locations. These rituals presented opportunities to remember, connect with and share stories of their absent children as a couple and as a family. These rituals were very important for couples and were continued many years after the death of their baby.

At times, the chapter remaining open presented a challenge for parents as the storylines became tangled and hard to separate. At times, a few parents found themselves comparing their present children to the absent child, or children. This comparison led to difficult thoughts of what the absent child might be like and whether they may be in some ways more connected to the absent child if they had survived. For a few parents, these thoughts brought up the dilemma of thinking about if the absent child was present, whether their surviving children would exist. The parents affected in this way felt this was unhelpful and made conscious efforts not to engage in this thinking, however, naturally, as the chapter remains open, it can be difficult for parents to avoid.

At times, parents were focused on the chapter of their baby loss, and it became more difficult to remain present within their current and emerging storyline with surviving children. These times tended to be during important dates, significant family events and milestones for both the babies lost and the children present. Below, Freya and Ethan describe milestones as complex, and it feels as though the intermingling of storylines prevents them from being able to stay fully present and celebrate their living child's milestones.

Freya: They're [milestones are] all bittersweet... I think they're all... everything about being a parent when you've lost is bittersweet.

Ethan: Yeah.

Freya: 'cause it's like every time Lucas does something, it's like you're really pleased and you're proud, but then you realize you're never gonna get to see your other kids do it. And we talk about that happening a lot in the future being prepared for it, like taking him to nursery for the first time, like taking him swimming for the first time and like...

Ethan: Yeah, like literally everything. Every milestone is, like you said, bittersweet.

Freya: Yeah. Everything's bittersweet with loss. So just.. Yeah... nothing's simple. Nothing's happy or sad. Everything's just complicated.

- *Freya and Ethan*

Parenting a child born subsequent to baby loss presented parents with many reminders of their loss. These reminders often served as emotional triggers to parents. During and often for a period following these triggers, parents again felt more situated in the chapter of loss, rather than the present. Examples of triggers included hospital visits, seeing baby dolls and sickness within the family. At these times, parents struggled to stay firmly in the present and focus on the surviving child, instead, they were transported back to their loss narrative. This also occurred in at least 5 of the interviews when questions were asked about the surviving child and the parents reverted back to discussing the child that died and sometimes found it difficult to find their way back to the narrative of their surviving children. This showed how complex and intertwined the storylines of parenting could be.

A few parents felt that the absent character was stuck in time, they always pictured them as a baby, as they were when they died, and were unable to picture them changing over time. For these parents, the two storylines became easier to disentangle when their subsequent children developed beyond infancy. As they looked less like the absent character, it became easier to make distinctions.

3.3.2 Gendered Discourses

There were some stories told that were discursively linked to parents' gender, through embodied experiences and wider societal discourses about the meaning of baby loss and becoming parents to subsequent children. It is important to note that these stories were not representative of the majority of fathers or mothers interviewed. However, they are important to recognise in exploring the different ways in which the parenting of children following baby loss could be affected. In line with the research aims, it is especially poignant that the unique narratives of fatherhood are included to highlight some of the contrasting ways that parenting subsequent children is experienced.

For some of the fathers, it felt important to them to present a public story that their parenting was unaffected by loss. Similarly, some fathers were keen to present a story of parenting that was not in any way negatively impacted by loss. For example, the story offered by some fathers portrayed that they were only affected by baby loss in wanting to have a close relationship with their living children. However, these narratives were then countered by stories told by their partner or themselves as the interview developed. This suggested that they had a public story of being unaffected or only positively impacted and a personal or actioned story that differed from this. For example, John and Ben went on to say that they may be "subconsciously" affected by their experience of baby loss. The narrative of their subconscious may be indicative of their more personal story, which they may feel less able to share publicly with a female interviewer. For John, on a subconscious level, he wanted to protect his rainbow child. Ben shared a story in which his parenting was unaffected by baby loss and most likely became more relaxed. He explained that he was very close with his rainbow child as they got on very well. However, he later wondered whether, on a subconscious level, this may be driven by his prior experience of baby loss. Below is a

section of the interview with Ben and Anita in which a more personal narrative for Ben is given that Anita believes shows how Ben's parenting may be affected by loss. This suggests that there may be different levels to some parent's narratives, between their public and their personal stories. Ben's public story is unaffected, whereas his personal story revealed through actions and the stories shared by his partner, tell a story of seeking closeness and safety.

Anita: Ohh, and about the strap.. that's probably linked to it [baby loss]. That's definitely linked to it, right? So we've got a baby carrier, OK? And Jacob, he he's not the lightest of babies, OK? He's a little chunky monkey, now he's 20 months old soon, he should not be in that baby carrier and he can barely squeeze into it.. I mean, he's bursting out. There's one button we can't do up, isn't there? But he insists on using that baby carrier whenever he can. Now he can walk, he can run. He can do it all. If I take him out, I will use the umm.. the buggy, the lovely buggy that we've got I'll use that and you know, and we bought, I bought reins for when we went to the on holiday in half term, I bought reins for the beach, you know fine, he insists on using that and he never ever did that with Sebastian. And I've said to him, we used it Saturday night, and I said to him umm, OK, there's a crowd where we're going, fair enough, use the strap, but I really do think that's the last occasion and he's trying to stretch it out till the end of the year now.

Ben: I don't use it that much anymore.

Anita: He uses it all the time, well I don't know what you do when I'm not here.

Ben: Yeah, I I can't.. Again, it's something that I can't explain. I remember trying to do it with Sebastian.. A few times and I can't remember, I think when I first wanted to to to do it, I think because Sebastian was so tiny, and was for quite some time, he didn't really catch up to to perhaps what he's weight should have been for his age until he was close to two, so I

never really, I never really got that opportunity with Sebastian. Umm So I think that's one of the reasons. Um but again, there's probably some link to Jacob being the rainbow baby and I don't know, I mean, I like I said I can't give you an answer, perhaps on some strange level, it's just my way to be kind of attached to him and or him attached to me. And you know, perhaps on some level that just I feel safer that way because of what's happened in the past. But but again, like I said, it's not something that I'm aware of, so you'd have to, you know, dive deep into my brain to probably get that answer. Umm but yeah, I mean, it's not even something that I think about, I just know that I like doing it, so I'd say it's probably linked to both.

- Anita & Ben

For some of the fathers interviewed, it appears that they have continued to take the supporter role that they may have taken when their baby died. They continue to support the mother and their living children and feel that this is their primary role. These fathers sometimes spoke much less during the interviews and appeared to assume that the space was predominantly for the mothers. For example, in 11 of the 15 interviews, the mother spoke first and therefore began the couple's narrative of parenting and the fathers then joined. In 4 of the interviews, fathers offered emotional support to the mothers as their narratives were shared. This was seen by offering tissues, providing a comforting touch and filling in the narrative when a mother felt too emotional to speak. In one interview, when the couple's children entered the room asking questions, the father excused himself to help re-settle the children back to bed. This helped support the mother to share her story and showed great care towards his children, however, it may also indicate that he felt of secondary importance in the couple's parenting narrative. It was clear that fathers taking the role of supporter was an important role for these fathers and likely supported how they were parenting their living

children. However, it is important to consider what is not said and to read between the lines of the father's narratives.

Alternatively, some narratives shared appeared to illustrate that parenting practices may be affected by loss in a manner only experienced by mothers. For two of the mothers interviewed, their experience of baby loss instilled a sense that they were not able to keep their children safe and therefore not good enough as mothers. For these mothers, parenting a child subsequent to baby loss caused them to step back from parenting. These mothers expressed an innate sense that they would not be able to protect their children. This led them to take a more futile stance and share a public story that always protecting their children is not feasible. This is demonstrated in a story below that Jane shares of her sense of lack of control. However, through the stories told, it appeared that they also had a personal story in which they were still very much present and providing for their children, but at times needed to step back when overwhelmed by the feelings caused by their baby loss experiences. This is shown in the story shared below by Jane.

Jane: ...this fact that I cannot control makes me more relaxed because I just feel that I will go with the flow, whatever happens. Anyway, I can't control and this umm is contrary to what Harry said about being an helicopter parent and being always there, making sure that he's not falling he's not.. I'm not like that and I didn't become like that and I've never been like that and I maybe I am a bit more than... much less than him, but maybe I'm a bit more compared to what I would have, what I would have been, but I'm not like that because I I feel that in any case, even if I'm there all the time, if he has to die, that will happen when I'm not watching.. That's what happened with Mason, because I I mean, I was pregnant 37 weeks and and I really could feel him all the time, everything he was doing and and he died and I didn't realize. So if I cannot realize one that my son is dying and and he's inside my body, I

just I give up, I'm not controlling his death or life, if he's gonna die, he's gonna die I cannot control that so I would I would be more happy for him to fall and and hurt without me being there checking out because anyway I feel I cannot control that either.

Harry: No, I don't agree with you. I don't.

Jane: I know and that that goes with the with the pessimism that I was talking about, which is is really not something nice to think about. But that's what I think. And obviously I'm I'm there, I'm paying attention, I'm watching him and I am I am uhh careful but I I I wouldn't feel that I I will I will be enough to protect him. I would never tell him you are OK because your mum is here.

- *Jane & Harry*

3.4 Narrative Types

The couples interviewed tended to tell stories which broadly fit into two genres; one of risk consciousness, and one of gratitude. Couples did not always tell stories in only one of these genres but often moved between the two. Sometimes one partner would share a narrative predominantly fitting one type, and their partner would be more aligned with the other. This was not always problematic and sometimes balanced their collective approach to parenting. The way the narrative types interacted will be further explored in the discussion chapter.

3.4.1 Stories of Risk Consciousness

Baby loss was often spoken about as a pivotal point in the couple's lives from which their stories were forever changed. Couples referred to their lives before and after loss and recognised that the stories they told since baby loss are narrated through an updated lens. This updated lens differed between couples but encompassed a re-prioritisation of values in light

of an increased sense of mortality. In line with their shifted worldview, parents interviewed were now raising their subsequent children with a heightened sense of risk consciousness. Parents were constantly risk assessing and then making decisions based on the outcomes of such assessments. Though this is likely true for most parents, for these parents the risk consciousness was heightened following baby loss and this frequently dominated parents' narratives.

Parents' risk consciousness increased in various ways, for some it caused parents to overestimate the likelihood of danger. Parents described preparing for 'when' rather than 'if' something bad would happen. This was especially pertinent during the subsequent pregnancies but persisted into parenting the subsequent children throughout their childhood. A pertinent example of this expectation of the worst-case scenario was illustrated by Sharon and Mathias when they explained that they had not expected their baby to survive and so had not prepared for bringing them home.

Mathias: we didn't buy anything for Emma until she was born.

Sharon: we bought one outfit and the car...

Mathias: We bought a going home outfit just in case she needed to be buried in it.

Sharon: And Toys'R-, Babies-R-Us got the order and there was this big kaffuffle, where I remember writing a letter to them saying you have no idea how much effort it's taken to me to choose this outfit, which may be the outfit that my child comes home in or gets buried in.. And and I think once they got that, they went 'ohh' and sort of sorted it out for us. But it's simple things like her coming home from hospital outfit became such a big thing and a big decision. So I remember we we we didn't have a pram for her so we walked down the high street, well, he did with her in his arms because we hadn't bought.. We bought a pram for the boys and we spent ages and bought this perfect pram which I still see out and about now and and I loved that pram, it was a beautiful twin pram. I loved it. But, so when they

died, we returned it and that paid for their funeral. So then when it came to buying a pram for Emma, we didn't. We didn't until she was two weeks old. We went down the high street and just went and bought the first pram that would fit in our car.

Mathias: We didn't even tell people about Emma.

Sharon: Yeah.

Mathias: Until she was born. We told like a handful of people.

Sharon: My mum knew at 18 weeks because I thought I was showing too much. Umm Mathias didn't tell his best friend until in the hospital after she's been born. My best friend knew. But we had people around for coffee the week before and I just had my bag on my lap and we didn't tell them.

- Sharon and Mathias

This pattern of thinking was demonstrated in other parents' stories as they spoke about taking measures to either prevent or feel more able to manage when things go wrong. Alyssa and Fred spoke about having more rules than other families that they were close with in order to keep their children safe. Two couples completed infant and paediatric first aid courses following the birth of their rainbow baby to feel able to respond and keep their children safe.

The experience of losing a baby demonstrated to parents that a crisis can happen very quickly and unpredictably. This left parents with the sense that life can be fragile and that risks are very real. Almost all the couples explained that they had not expected their baby to die and that the chances of anything going wrong had been very small. Therefore, these parents were no longer comforted by improbabilities of highly unlikely risks. Their perception of risk is therefore increased, encouraging hypervigilance when parenting children born after their experience of baby loss.

This heightened sense of risk caused increased checking and monitoring of rainbow babies by parents. The majority of parents described frequently checking their children's breathing when they were sleeping. Alyssa and Fred explained that they still do this, even though their children are 6 and 7 years old. Parents described using multiple methods to monitor their children's safety and well-being, including using heat detectors in their children's rooms and tracking apps on their children's phones. Alyssa and Fred described doing lots of research to find the best ways of monitoring and keeping their child safe. They bought a sock from the United States that monitors their baby's health and engaged in months of research to determine the safest car seat for their child.

In line with baby loss increasing parental sensitivity to the likelihood of a crisis occurring, parents from more than half of the couples described more frequent thoughts of death. For some, these presented as sudden, intrusive thoughts and images of their child or partner dying. For others, these thoughts started as small worries that spiralled into worst-case scenarios and became difficult to let go of. It appeared that for many parents, typical worries became amplified by their experience of baby loss.

Parents made efforts to protect their children from harm by staying close and limiting the number of trusted people in their lives. For example, they would be very selective about who they allowed their children to stay with or be cared for by. At least seven parents described staying close to their children whilst they played in order to keep them safe and be present if something bad were to happen.

Almost all of the couples were aware of their increased risk consciousness. This awareness itself sometimes further added to parents' worries about the potential impact of their risk consciousness on their children. They found themselves battling with wanting to keep their children safe and not wanting to limit their children's experiences or pass on any anxiety. Parents often therefore made conscious efforts to counterbalance their heightened

risk consciousness. Some parents did this by consciously overriding their fears and letting their children take risks in order to mask their fear from children. Another way of counterbalancing risk consciousness was to distinguish what to worry about and what not to worry about. Nine of the couples decided that it was not worth worrying about anything that would not be vital to the well-being or safety of their children. Parents described not worrying about implementing suggested sleep routines, academic grades, or their children's diet. They were supportive of their children's health and wellbeing; however, they did not worry about them going to bed a little later than suggested or eating a bit more sugar than recommended. Anita and Ben describe this prioritisation in terms of differences in their parenting style from the child they had before their baby loss and the child they had afterwards.

So sometimes I think we're more relaxed because it's just like this, this I I do have that feeling of.. You know what, he he's here and that there's nothing more important than that. So OK, if he is a bit late to going to bed, or if he eats a bit of chocolate, like, I'm not gonna. I'm not gonna, you know, lose any sleep over it because you know he's here and I think that's the overwhelming feeling for me is that he's here. So everything else is whatever. Really.

- Anita

In the following narrative, Blake describes the process of risk assessing that she goes through on a daily basis and how she counterbalances this by choosing what to worry about. Edward also demonstrates his awareness of his heightened risk consciousness and desire to counterbalance this.

Blake: ...But you know what, I just had the best time with her as a baby. She was brilliant, really easy, totally bonded with her. The only thing I would say in terms of how the parenting probably affected her is that.. I probably didn't sweat, and I still don't. And Ed will back me up on this. I don't sweat the small stuff... Which might look like. Sometimes I let a lot

of things go.. Because.. I am very, very aware that every day with my children, unfortunately I do live like this... Every day could be the last.... So. It's really hard because you you, you overthink things. Umm. And it's little it's silly things. It's like when I'm putting them in the car. And to decide which side to set on, I have to.. it's it's such a process for me. I have to have a chat with myself about every little decision. Is that gonna be the right side of the car? If they, if I have an accident.. And I've said that they've sat on the left or the right and something happens... Is that gonna come back on me and my decisions and they see that partly stems? It's from, obviously the guilt of what happened, even though it wasn't directly responsible. If things had happened differently, they would have been a different outcome.

Researcher: Mmm.

Blake: So for me, parenting can sometimes be quite overwhelming because when you have to make decisions... I I worry that every decision's gonna be the wrong one... So sometimes because it's so tiring, I let little things go. They're probably get away with more than they should. And you know, because yeah, you just also so kind of I guess grateful for every day that you have with them that you don't wanna ruin it with like stupid little things that you moaning about and you know that kind of thing. So I'm probably a lot more easy going.

Edward: Yeah. I mean and you know we're we're definitely not overprotective parents but equally you know having lost a child that is that's huge I think for both of us is that they are definitely protected and there there there's an interesting.. I'm a big fan of pixar by the way. And then and there. But there's a line from from Finding Nemo that I love where Nemo's, Nemo's dad, is talking about wanting to protect them from everything. And one of the other fish turns around and says, but if you don't let anything happen to him, then nothing will happen to him. And it's one of those things that... I've got to constantly remind ourselves and demand of that because, you know, you know, we, we... And as I say, it's not overly

protective, but we're quite happy for them to just be at home because then we can look after them and we know they're safe.

- Blake & Edward

Another way of countering risk consciousness was for parents to recognise the resilience they showed following the loss of their baby. These parents managed worries as they felt that the worst-case scenario had already happened and they were now more equipped to manage any unwelcome scenario that may come their way. The following narrative demonstrates how Sharon cycles between her heightened risk consciousness and counteracting this.

Sharon: I think it influences quite a lot and personally I go through a lot of swings. I'll go through the whole helicopter parent where you're hovering over them. You don't want anything to happen to them because you're so scared of, you know, the feelings that come with that.. To, yeah... Why don't you climb that tree? What's the worst can happen? You break a leg? We can deal with that. So it it does go worldly... You know, you're really OK with anything happening because you can deal with that to I'm not letting you out my site. So it's just trying to square those those up. So it does. It does affect it, yeah, definitely.

Mathias: But I agree, it's that that, that hypervigilance versus almost la c'est faire..

Sharon: Yeah.

Mathias: But I think when it does comes to hypervigilance, it's it's communicating across to the children where it's coming from, umm, we're we're not being neurotic.. This is born of a real fear. Umm. And I think what surprised me about things, is it hasn't been with all of them, but with some of our our children, there is this overwhelming dread that something terrible is going to happen, particularly with our youngest daughter Louise, or felt quite keenly convinced that I would go into a room and not find her breathing.

- Sharon and Mathias

3.4.2 Stories of Gratitude

"There's that like rainbow child thing you know, she's the one who sort of saved our lives and you know, brought us back into the world."

– Edward

At least one parent in each couple expressed gratitude for the safe arrival of their rainbow baby and all parents reported a sense of relief. This sense of gratitude appeared to be the dominating narrative at times for at least one parent in each couple and continued to guide parents in raising their children. This was the case for Lars, as shown in the following extract.

I'm.. Deep down, I'm resoundingly happy that they're here all the time, and even when I'm completely frustrated and fed up with them because they're crying or not eating a meal or just being a pain because they're throwing toys everywhere and and you're tired and... I'm still, I've still got this resounding happiness that they're both there all the time. But what I will never know, is if that's something that every parent has because you're a parent and they're obviously your your child, or if that's something that's come about because of the fact that I know what the alternative is.

– Lars

The gratitude felt by parents appears to be rooted in a number of factors. Firstly, gratitude may stem from the sense of relief they feel following a pregnancy fraught with fear, and as Lars described, knowing “*what the alternative is*”. Secondly, many parents felt that their rainbow baby had in some way saved them from an otherwise dark narrative of only grief and loss. Daria was one of the parents who felt this way and explained that this meant she would always have a special bond with her rainbow baby.

*Yeah um, I mean, like I say, I've just, I have always just protected him so much, haven't I? Because he was my rainbow baby and he saved, you know, saved me.. he did, he saved me *crying*. So I'll always have that like special bond for him. And he's such a sensitive soul. Like he will sit there and if I get upset, he'll come and cuddle me and he'll get upset because I'm upset, but so yeah, it was.. It's just something special with him um, that like, it's hard to describe really, but I guess it's just a, I don't know, a rainbow baby, baby sort of thing.*

– Daria

This sense of relief and gratitude manifested in different ways for parents. Fourteen of the fifteen couples spoke about prioritising and treasuring quality time with their child and emphasised the importance of building and maintaining a close relationship with their children. Many parents shared that loss had shifted their worldview and caused them to re-prioritise what was important to them. This was often prompted by an awareness of the fragility of life and therefore the importance of spending time with family and making the most of the time they have together.

For some, particularly those parents who felt their rainbow baby had saved them, they perceived their rainbow baby as special and therefore developed and maintained a very close connection with the child. For Alyssa and Fred, they felt that their rainbow baby, Isabella, was sent as an angel by Sofia. Alyssa described seeing Sofia in Isabella's eyes, therefore, staying close to and protecting Isabella may also have been a way of staying close to the child they lost, Sofia.

Eight of the couples felt that they were more patient with their child born subsequent to their baby loss. These parents' sense of gratitude allowed them to look past some of the

challenges of parenting, such as sleepless nights. Some of these parents commented that they complained less than other parents who had not experienced baby loss. Two parents commented that they felt unable to complain and did not appreciate other parents complaining as they felt lucky to have living children and felt other parents should recognise this too.

In line with parents' shifted worldview following baby loss, many parents expressed feeling that they had changed as people after baby loss. For some parents this was told as a negative change, Jane described herself as more negative and less able to feel happy. However, several parents felt they had become more empathic and compassionate, which had a positive impact in different areas of their lives. They felt this would be positive in their ability to parent and hoped their rainbow baby would feel able to come to them to talk about difficulties.

In the narratives guided by gratitude, this appeared to motivate parents to do, be a provide as much as they could for their rainbow children. There was recognition within the narratives that this is natural for many parents, however, these parents felt additionally motivated. For some parents, including Vicky, this was expressed as a way of making up for being unable to parent and provide for the child they lost.

Vicky: I think the the main way I think it's it's impacted us is is just feeling very protective and wanting to, to just nurture every single aspect of his life, to within an inch of his life, because we know precious that is, and how quickly things can change, and I think that's the main thing for me. That is, you know, you just want to be, you know, the best version of yourself as possible for them. So that they have everything that Cassius won't have. Basically, I think that's kind of the main thing for me..

Elijah: I think it's just presence for me.

Vicky: Yeah, and being available for him, making sure that he has us all the time, and anything he needs growing up, and emotionally, that he gets from us too.

– Vicky & Elijah

Vicky's partner, Elijah, goes on to explain that for him, gratitude and a shifted worldview have motivated him to prioritise quality time with their rainbow baby. When sharing his narrative, he shares that he feels less need for material gifts and instead prefers to ensure he spends plenty of time with their rainbow baby and shifted his working pattern to better facilitate this.

4 Discussion Chapter

4.1 Chapter Overview

First, the findings are discussed in relation to the wider literature, societal discourse and in the context of the research interview itself. I will also discuss how the findings interact with one another to form the couple's narratives as whole stories. I will consider the study's strengths and limitations before offering suggestions for future research. I will then discuss the clinical relevance of the study's findings and make suggestions for policy and practice. Finally, I offer some of my own reflections on the process of conducting and writing the current research.

4.2 Summary of Findings

The main aim of the current study is to consider the impact of prior perinatal loss on subsequent parenting through the experiences of couples. The research objectives are to explore how couples raise a child in the context of prior perinatal loss and to situate fathers within the narrative of perinatal loss.

The findings of the current study support literature suggesting perinatal loss is a profound life event with long-term implications (Currie et al., 2019). Furthermore, the current findings bolster and build on existing literature suggesting that raising a child following baby loss is a complex process filled with mixed emotions. I will address each of the main findings in the context of the existing literature and wider societal discourse drawing on in-depth data from parents currently navigating this complex journey.

4.2.1 *The Chapter Stays Open*

Findings that the chapter of baby loss stays open supports and builds on the findings of the literature synthesis that parents maintain an ongoing relationship with the child they lost. The findings therefore challenge earlier theories of grief, such as those of Freud (1917) and Worden (1982) and support Rando's (1991) suggestion that these models need revising. The findings align with updated theories of grief such as Davies' (2004) notion of continuing bonds. Stroebe and Schut (2005) suggested further research is needed to explore whether continuing bonds is a useful process for the bereaved. From the data collected, it appeared that this was a useful and important process for the couples and all the parents were keen to share their story of baby loss with me in the confidential interview setting. This supports Michael White's (1988) view that finding ways of continuing to connect with the deceased is a helpful process. Where previous literature demonstrated the importance of storytelling for mothers, the current findings found that this was important for both mothers and fathers. For

the most part, parents enjoyed connecting with their baby who died and cherished developing this relationship. However, the findings do also suggest that this can at times present a challenge for parents in staying fully present and focused on their surviving child.

The findings reflect a similar process to that described by Hooghe et al. (2012) in which the couple studied oscillated between confronting and avoiding the pain of their loss. The current study saw that long after the birth of subsequent children, parents oscillate between reconnecting to their baby that died and connecting to the present moment. In line with Clark et al.'s (2021) findings that grief intensifies on significant dates; parents were more connected with their baby that died at these times.

The current findings show that parents tend to find ways of including their subsequent children in their ongoing relationship with the baby that died. Rituals and storytelling become adapted to include the surviving children and this remains present in their lives and couples expressed their intentions for this to continue for generations to come.

4.2.2 Gendered Discourses

The current narratives reveal that there are some ways in which parenting children born subsequent to loss is impacted that are specific to gender. It was seen that fathers may hold a public story that they share with others more readily. In this story, they describe their parenting as unaffected, or only positively affected, by loss. This public narrative may also be guided by fulfilling the role of the supporter for the rest of the family. This was congruent with the systematic literature review presented in Chapter 1 that showed men tend to take a supporting role following baby loss (Abboud & Liamputtong, 2005; Avelin et al., 2013; Brierly, 2017; Dickerson, 2016; Hamama-Raz et al., 2010; Jones-Peebles, 2012; Lang et al., 2011; Tanacioğlu-Aydın & Erdur-Baker, 2022). The current findings suggest that fathers sometimes continue to assume this role and may therefore feel they have a secondary role in the sphere of parenting when raising a child born subsequent to baby loss.

However, it was identified that fathers also held a more personal narrative in which their parenting was affected by their experience of baby loss. Whilst their public narrative was readily shared by fathers, their personal stories took longer to share and discuss. Their personal stories were only shared once a level of trust had been established within the research interview, or they were shared on the father's behalf by their partners. Throughout the interviews, personal stories could be seen by the actions and events described by fathers, though they were not explicitly authored as showing that they were affected. Fathers' personal stories may have been made more accessible as the interviews were conducted conjointly with couples. Existing literature shows that mothers are often in control of the domestic, or private, sphere and therefore may feel more readily able to share more personal stories, whereas fathers are likely less practised in this (Parsons & Bales, 1956). Day (2001, p. 116) explores the construction of masculinity in relation to women's fear and writes that "public space is a central stage for performances of gender identities, including masculinity". This is interesting in thinking of the construction of narratives and their performative nature. Though the interview topics of baby loss and parenting are personal, the nature of the interview means the story has become public and therefore may influence some men to feel the need to perform traditional masculine ideals. This may also mean that when interviewing the couples together, fathers relied on the mothers to reveal more personal stories, whilst keeping their part of the couple's narrative as a more public story expected to be told by a man upholding his masculinity. In a similar vein, societal discourses on fatherhood traditionally stipulate the role of the father as a stoic provider (Davidoff & Hall, 2018). This would also influence fathers to share more stories of being unaffected and strong in order to support their family, whilst keeping stories of grief to themselves. The public stories told by fathers were likely to be seen as more publicly favourable due to discourses concerning masculinity and fatherhood. Discourses of masculinity are ever-changing, but traditionally

hold that a man in the public domain should present himself as strong and give little away (Anderson, 1997). Similarly, Hamama-Raz et al. (2010) stated that men repress more painful emotions which is congruent with men telling more positive stories and discounting more challenging parts of their stories. Ben, for example, may have been influenced by the wider masculine discourse that he should be unaffected by grief. He may also be affected by a societal discourse that pushes parents to only present stories of ‘perfect’ parenting. Seeking closeness due to a positive relationship feels more acceptable than to say he is seeking closeness to protect his child, or due to fear of losing his child. It may not fall in line with the role of being a man to share a public story guided by fear, or risk consciousness; similar findings were seen when men in Ghana spoke about their experiences of the COVID-19 pandemic; their desire to comply with societal expectations of gender roles led to these men suppressing expressions of fear (Diabah et al., 2023). There are other studies which also discuss the societal expectations placed on men in presenting as “fearless” (Goodey, 1997, p. 401).

It is important to note that the majority of the participating fathers were very open and readily shared personal stories of how their parenting was impacted by their experience of loss. However, it felt important to include the lesser-told stories that appear to reflect masculine discourses as these may be indicative of the voices not heard in this research. During recruitment, 6 mothers could not participate as the father did not want to be involved, these fathers may have avoided participation due to not wanting to bring personal stories to a public audience. There were no instances of fathers being prevented from taking part because mothers did not want to be interviewed. The research has been conducted within a period of cultural shift, where the role of fatherhood is changing from one of practical and financial support to one of increased emotional engagement and more hands-on caregiving (Dermott, 2003; Hobson & Morgan, 2002; Fatherhood Institute, 2023; Roberts, 2013). This may

contribute to the majority of fathers' feeling able to voice the impact of their grief, but simultaneously explain why others felt unable to do this so readily.

Gender differences were also evident in the literature review looking at the impact of baby loss on parents. Within this, Lang et al. (2011) found that women needed to talk for longer about their loss than men, this may in part contribute to women being better versed in storytelling in the realm of how they are impacted by baby loss. This was enacted in some of the research interviews where it was clear that the couples automatically positioned the mother as the primary narrator of their stories of loss and parenting. It may also be easier for women to share personal stories as they may have been more likely to practice this with friends and family throughout their lives. Tannen (1990) writes that whilst men feel more comfortable storytelling in public domains and sharing stories which serve to maintain their social status, women are more comfortable talking in the private domain and using language which aims to relate to and connect with others. The difference in these aims may contribute to mothers feeling more able to share imperfect and relatable stories, without the need to filter stories to maintain societal status. Similarly, Duncombe and Marsden (1995) discuss that women are more expressive and take more responsibility in the private sphere of heterosexual couple's narratives. Due to the socially constructed division of typical parental roles, mothers are more likely to be spending time interacting with and exchanging stories with other parents through baby groups and taking children to school. They may therefore be more exposed to stories that do not draw attention to only 'perfect' parenting. Whereas fathers may be more used to stories of professionalism and competence and therefore feel less comfortable sharing personal stories that may not fit their idea of 'perfect' parenting (Duncombe & Marsden, 1995).

The stories shared that were specific to mothers' experiences of raising a child in the context of prior perinatal loss, showed mothers struggling to identify themselves as someone who would be able to protect their child. For this reason, they shared a story in which they described themselves as taking a step back from parenting. Similarly to the father-specific stories; these mothers shared a public story of detachment, but a differing personal story could also be seen. Mothers' personal stories showed mothers doing their best to care for and protect their children born subsequent to loss. Mothers' personal stories were drawn out in a similar way to those of fathers. They were sometimes told by their partners or could be witnessed through the actions and events embedded in the mothers' stories, though they were not explicitly named. For example, the mothers may clearly say they have been stepping back from parenting, but when they tell stories of family life, it is clear that they are very much present and caring for their child. Mother's public stories may serve to protect them from a perceived sense of future failure. For example, by sharing a story where failure or risk is predicted, they are protecting themselves from a future story of being blindsided or failing to see something going wrong, mirroring the lack of control they experienced at the time of their baby loss. It may feel too scary to share a public story of protection as if something were to happen to their children again, it would once again feel like a failure. Mothers' public and personal stories of parenting after loss appear to be closely linked with their experience of loss as a personal failure. This sense of self-blame experienced by mothers has been widely reported elsewhere (Abboud & Liamputtong, 2005; Brierly, 2017; Dickerson, 2016; Kristvik, 2022; Nuzum et al., 2018; Steele, 2023; Tanacioğlu-Aydın & Erdur-Baker, 2022). Nuzum et al. (2018) showed mothers changing their behaviours in response to feeling responsible for the loss of their baby. The current study sheds light on how these behavioural changes develop following the birth of their subsequent children.

These mothers' narratives are situated in a cultural context where attachment between parents and their children is highly encouraged, and this onus is primarily placed on mothers. The National Health Service promotes ways of parents bonding with their children after birth, such as skin-to-skin contact (National Health Service, 2022). Experts encourage primary caregivers to curate a close attachment with infants (Sears & Sears, 2001). Since psychological frameworks were developed suggesting that early infant experiences determine children's mental health later in life, parents became more responsible for their children's outcomes. Mothers who were traditionally viewed as the primary caregivers were especially scrutinised in this dyad. For example, Bowlby (1951) presented the idea of 'maternal deprivation', in which he suggested that if a child's mother was absent, physically or emotionally, during the child's formative period of attachment, this could lead to adverse pathological outcomes for the child. These discourses likely have a complex interaction with maternal narratives; they likely add to feelings of responsibility and failure. They likely also cause a great deal of conflict in mothers who tell a public story of detachment to protect themselves from further perceived failure as they are simultaneously under pressure to form close attachments with their children.

Attachment theory suggests parents need to foster and maintain a close and responsive relationship to their child to ensure the child's successful emotional well-being and development. In light of mothers sometimes needing to take a step back from parenting, this suggests that the experience of baby loss could have an adverse effect on children born subsequently. However, attachment theory has since been critiqued and it is suggested that families can adapt to allow for both attachment and detachment. Eyer (1992) criticised attachment theory suggesting that a child is not only reliant on one consistent primary caregiver and a critical period, instead, she argued that attachment can be dynamic and

change. This suggests that in periods where the mother may need to step back, the father or other caregivers can assist in ensuring the child is securely attached.

Within the current cultural climate, there is a push towards increased eco-consciousness, such as consuming more natural foods, using natural remedies, and avoiding hyper man-made consumerism. This has come to affect parenting as there is a push towards 'natural' parenting styles. For motherhood, this can be seen in a push towards breastfeeding and increased negative judgement where mothers are using formula. Even formula adverts try to appeal to being natural and as close as possible to breastfeeding. This discourse promotes closeness between a mother and her baby, as seen in the primate world, by using carry slings rather than pushchairs and so on. This encouraged parenting style appears to assimilate to following natural instincts and at first glance appears to promote mothers' closeness to their baby and view mothers stepping back as harmful. However, in line with updated theories of attachment and knowing about the lasting impact of grief and the importance of continuing bonds with the baby lost, I feel it can be argued that stepping back at times is also encompassed in a natural style of parenting. So long as a child's needs are still being met, which the mothers interviewed made clear to be the case, it seems appropriate that at times the mother may step back and others may assist in parenting.

The process of detachment experienced by these mothers, within a culture of attachment, may be experienced as isolating. Faircloth (2024) writes that putting responsibility on mothers and pitting them against each other leads to mothers not being able to reach out to one another for support. This isolation reduces potentially positive opportunities for community support in raising children. Mothers sharing their stories of detachment may help to elicit this external support and therefore play an important role during their storytelling.

Literature highlights that contemporary parenting is more demanding than in previous years. Despite mothers now making up 50% of the workforce, they are still often considered to be their children's primary caregivers (Dunlop, 2009). Furthermore, Douglas and Michaels (2004) comment on the US media portrayal of motherhood as an unrealistically positive and fulfilling role. They comment that though this is recognised as unrealistic, it still creates a powerful discourse and societal expectation on mothers which can cause mothers to experience a sense of failure when not lived up to. These ideals are further exacerbated by social media (Scheibling & Milkie, 2023). The increased pressures of motherhood are likely to place an even greater strain on mothers who have experienced a prior baby loss. These mothers contend with a societal expectation to be even closer and more grateful for their rainbow child after their baby loss.

The stories in which mothers felt disconnected from their role of mother follow on from the disruption of roles evidenced in the line of argument crafted through conducting the meta-ethnography. It may be that for some mothers, the arrival of their rainbow baby may help to stabilise their role, or self-identity, as a mother. This would be supported by Currie et al.'s (2019) findings that subsequent children renew their parent's sense of purpose. However, for mothers who have not engaged in this cognitive process, their role may have remained disrupted. It is again important to note that these mothers' public narratives of stepping back and personal narratives of caring and protection were only seen in a minority of participating mothers. However, once again, they are important to document as they may reflect the stories not heard in this research. As they are less 'normative' within wider societal discourses, the mothers holding stories of stepping back from parenting may choose not to participate in research.

As the gendered discourses were only seen in a minority of the parents, the findings largely support King et al.'s (2021) findings that mothers and fathers had similar reactions to baby loss. As concluded in the literature review, mothers and fathers may have similar grief reactions but express these differently. Parents' public narratives may be more susceptible than their personal stories to the influence of cultural discourses and pressures.

4.2.3 Stories of Risk Consciousness

Previous research shows that baby loss causes increased anxiety during subsequent pregnancies (Abboud & Liamputtong, 2005; Cacciatore et al., 2008; Hooghe et al., 2012; Tanacioğlu-Aydın & Erdur-Baker, 2022; Jones-Peebles, 2012) and Cacciatore et al. (2021) found that baby loss led fathers to experience increased anxiety regarding losing further children. The current findings built on this reported understanding and highlighted that this manifested in parents as increased risk consciousness when raising their children born subsequent to baby loss.

Parenting roles and expectations have changed considerably over the years. As discussed when considering the development of motherhood, the development of psychological frameworks placing importance on early life experiences in the healthy development of children as adolescents and adults, placed an increased responsibility on parents. Determining 'good' parenting is bound to the neoliberal context of our society, encouraging more intensive parenting. Intensive parenting has gained prominence as a concept in contemporary society and refers to a style of parenting characterised by a high level of parental involvement, investment, and supervision in all aspects of a child's life (Jeziński & Wall, 2019; Shirani et al., 2012; Wall, 2022). Parenting literature and the media have promoted a parent-blaming discourse, directly linking poor parenting to adverse child outcomes (Teti & Cole, 2011; Stearns, 2003). Parental responsibility has therefore been

intensified and widened in scope as parents are now expected to constantly monitor where their children are and what they are doing (Holt et al., 2016). This appears intrinsically linked to a shift towards risk consciousness in parenting seen in the literature (Nelson, 2010; Day, 2024). The current findings suggest that the experience of baby loss further exacerbates risk consciousness for parents going on to raise a child born subsequent to their loss. For these parents, risk consciousness was heightened meaning they were expecting and detecting risk more frequently. When detected, the risk was also perceived as more likely to have graver consequences. There is a paucity of research exploring what the level of 'normative' parental worry would be, however, Fisak et al. (2012) identified that parents' most commonly reported worries regarding their children were concerning life success and physical well-being. The findings suggest that parents' experience of baby loss heightens worries regarding their children's well-being, whilst reducing worries regarding their children's life success.

Increased risk consciousness for these parents may be underpinned not only by a societal pressure to be increasingly aware of risk but also a perceived and felt sense of judgement from wider society that parents feel they were unable to keep their child that died safe and must now prove to others that they are able to keep their subsequent child safe. This may align with and build on Nuzum et al.'s (2018) findings that parents can experience shame when seeing other parents after losing a baby and other research showing that parents can experience a sense of personal failure following baby loss (Cacciatore, 2010; Hamama-Raz et al., 2010). It may be further underpinned by parents attempting to compensate for the lack of control that they felt at the time of their baby loss. Parents are currently situated in a culture of increased judgement and surveillance due to the rise of social media and 'expert' models of parenting suggesting there are right and wrong ways to raise children (Hays, 1996; Simmons & Simmons, 2020). This likely exacerbates the pressure felt by parents who have

experienced a baby loss to promote their child's well-being and therefore engage in intensive parenting rituals.

Whilst there is a culture of intensive parenting, simultaneously there exists a societal expectation for parents to promote independence in their children. Independence is seen as a valued and crucial developmental milestone for children to be able to successfully navigate adulthood, particularly in Western, individualistic societies. It seems that neoliberalist rationale promotes both intensive parenting and children becoming independent, however, this contradiction in expectations creates a double bind for parents. This double bind can lead to significant stress for parents as they navigate the complexities of balancing these contradictory expectations. Societal judgment and scrutiny can exacerbate these feelings as parents can be criticised for being over-protective and too lax in their approach, or even neglectful. The current findings suggest that parents who have experienced baby loss are also aware of and navigating this double bind. The findings suggest that though risk consciousness is heightened for these parents, their ability to navigate the double bind may be more developed and nuanced than other parents who have not experienced baby loss. It appears that parents who have experienced loss are able to filter out some less crucial worries regarding parenting and focus on keeping their child safe. They appear to be less negatively impacted by societal judgement regarding some specific parenting practices such as promoting the *right* way of sleeping. It seems that baby loss has allowed them to pay less attention to some societal pressures and be less vulnerable to criticism as their main objective is to keep their child safe and they know that the rest will happen naturally.

As the meta-ethnography suggested, baby loss can be a disruptive tragedy to the relational system in which parents become more isolated from their social network. This may have laid the foundations, alongside increased risk consciousness, for parents limiting the

number of trusted characters around them when raising their child born subsequent to their loss. This reduced circle of trusted characters may also help to limit judgment from others on particular parenting practices. Parents who have experienced baby loss were able to navigate the double bind as they were aware of their heightened risk consciousness. This awareness caused them to make concerted efforts to counterbalance risk consciousness to allow their child to gain independence, despite the anxiety they as parents may be holding. The findings therefore challenge the idea of the ‘vulnerable child syndrome’ (Davis et al., 1989).

4.2.4 Stories of Gratitude

In contemporary societal discourse, there is a pervasive narrative emphasizing the notion that parents should be grateful for their children and their role as parents. Parents are encouraged to express gratitude for the opportunity to nurture and raise their children, viewing parenthood as a privilege and a source of profound purpose in life. This discourse is perpetuated through various channels including social media, advertisements, and cultural narratives, which celebrate the joys of parenthood and is sometimes referred to as ‘toxic positivity’ (Goodman, 2022). Positivity and gratitude in parents are seen as conducive to creating positive outcomes for children and therefore further perpetuated in literature (Obeldobel & Kerns, 2021). This discourse is particularly pervasive for parents who have experienced a previous baby loss (Tommy’s, 2021). Parents in the current study shared narratives in which they felt very grateful for the safe arrival of their children born subsequent to perinatal loss. It is possible that parents’ experience of baby loss enhances feelings or gratitude towards their subsequent child, as they are aware of the alternative experience of their child not surviving. However, it must be considered that this narrative is enmeshed in the cultural narrative of gratitude and enhanced further by a cultural narrative assuming that having a child subsequent to loss may ‘resolve’ a family’s grief. The term ‘rainbow baby’ suggests that a baby born subsequent to loss is a rainbow, bringing light and

hope following a dark and stormy period of time. This metaphor feeds into the narrative of parents needing to feel grateful and wholly positive regarding their subsequent child. None of the parents in the current study reported that their subsequent child has stopped them from grieving for their baby loss, or taken away their sadness, hence 'The chapter stays open'. However, parents did express a sense that children born subsequent to loss saved them in some way from their grief. This is fitting with the term 'rainbow baby', but when thought of in combination with 'The chapter stays open', complexity is added to the rainbow metaphor. The subsequent child may bring open a positive new chapter, however, this is also fraught with increased risk consciousness and does not equate to the grief for the baby that died being resolved.

The current findings suggest that parents' gratitude was also underpinned by a sense of relief that their subsequent child survived. This relief remained and set a positive context for parenting. This reinforces findings from Currie et al. (2019) that children born subsequent to baby loss give parents a renewed sense of purpose. Similarly, having children after loss may facilitate the process of re-stabilising parental role expectations that were, as the meta-ethnography demonstrated, disrupted following baby loss. This feeling of gratitude meant that parents prioritised and treasured quality time with their children born subsequent to loss and valued maintaining a close relationship with their children. This gratitude also resulted in parents wanting to do as much as they could to support their children born subsequent to loss. For some, this may also be underpinned by parents' feelings of regret not taking opportunities to parent their babies who died, as shown by Nuzum et al. (2018).

Parents' gratitude for their children born after loss aligns with previous research by Campbell-Jackson et al. (2014) showing that parents view these children positively. However, while Campbell-Jackson et al. (2014) found difficulties in early attachment, the current study found this rarely happened and in the large majority of cases, early attachments

were guided by relief and though increased risk consciousness was present, parents were very much able to bond and form close attachments with their babies born subsequent to loss. This may be in part a result of couples becoming more isolated following baby loss which may emphasise the importance of closeness as a family unit. The process of loss being a disruptive tragedy to the relational system suggests that parents may still be in a state of re-adjustment and repair from this when they go on to have subsequent children. This likely plays a part in the findings that parents tend to have re-prioritised what is important to them in terms of who they are spending time with and with whom they are investing their efforts.

Though the wider discourse of parental gratitude can foster appreciation and positive attitudes towards parenting, it can inadvertently contribute to feelings of guilt or inadequacy in parents who struggle with the challenges and demands of caregiving. Thus, while gratitude for children is celebrated, it is important to recognise the complexities of parenthood and the diverse experiences of parents navigating their roles. This is particularly true for parents navigating their parental roles following baby loss as they are likely to feel increased pressure to conform to these cultural narratives.

4.3 The Intersection of Fear and Relief

It seems that the narrative types of risk consciousness and gratitude are underpinned by feelings of fear and relief. A fear of something bad happening to the subsequent child because of their experience of baby loss and relief at the survival of their subsequent child because of their experience of baby loss. Both narrative types of risk consciousness and gratitude are often intertwined. It appears that generally, each parent has one of these as their dominating narrative, however, they also access and connect with the other narrative type. Many of the parents hold both narrative types strongly and cycle between being guided by risk consciousness and fear or gratitude and relief.

The dominating narrative types are sometimes shared between the couple but can also be different between the couple. Many couples discussed their differing dominant narratives as being complimentary and felt it aided their parenting. For example, one parent may worry more and the other would help to soothe their partner by reminding them of their gratitude for their child. Similarly, as most parents hold both narratives, their sense of gratitude often tends to mediate their heightened sense of risk consciousness. In this way, the narrative types interact with one another. For example, when parents' narratives are being guided by gratitude and they choose to prioritise quality time and stay present with their surviving children, they want this to be a carefree time and therefore choose not to worry about certain behaviours or things that may bring any tension or negativity into the relationship or time spent together. Therefore, the narrative type of gratitude can at times facilitate parents' efforts to counterbalance their risk consciousness. Parents in this space did not feel obliged to worry about things that didn't feel detrimental to their parenting and instead, they embraced the warmth of family life. It could be said that narratives of gratitude help to mediate narratives of risk consciousness. The want to do everything for their rainbow baby stipulated in the gratitude narrative may also drive efforts to counterbalance risk consciousness, in wanting to ensure their surviving children are able to develop independent and fulfilling lives. This suggests that parents who have experienced baby loss may develop more nuanced ways of navigating the previously discussed double bind of parenting than parents who have not experienced baby loss.

Sharon, Mathias and Blake are good examples of parents cycling between heightened risk consciousness and *la c'est faire*. They demonstrate a nuanced sense of risk consciousness in parenting as though they are fearful of anything bad happening and they may risk assess more than other parents who have not experienced loss, they choose to worry much less than other parents when a risk is not perceived to be fatal. For example, Sharon and Mathias

shared a story of attending a scan appointment during pregnancy. They were told that their baby had a healthy heartbeat, and then the clinician went on to show them the arms and legs. Sharon and Mathias joked that they did not care about the latter, so long as their child had a healthy heartbeat, the rest was a bonus.

The gendered discourses also appear to weave into the dominant narrative type taken by each parent. It seemed that at first, fathers would tend to more readily share stories of gratitude and relief, whereas mothers would open with stories of risk consciousness and fear. As the interviews went on and couples built on and co-constructed their stories, these gendered stories dissipated and both mothers and fathers shared stories of both gratitude and risk consciousness. This is reflective of gendered discourses positing that fathers may be reluctant to share stories relating to fear in light of cultural ideals of masculinity and what it means to be a father (Connell, 2013). Similarly, mothers more readily sharing stories of fear and risk consciousness reflects a societal discourse placing females in positions of vulnerability and as more likely to experience fear (Mehta, 1999; Sandberg & Tollefsen, 2010). It is also known that women are more negatively evaluated for risk-taking than men, especially, it seems, within a family context (Donnelly, 2004). This may encourage women to share stories of risk consciousness to demonstrate their thoughtfulness regarding risks.

4.4 Strengths and Limitations

A limitation of narrative analysis, or qualitative methods more generally, is that the findings are subject to the researchers' own views and biases. I kept a reflective journal and used consultation with my supervisors to think about and limit the influence of this. For example, I wondered how my experience as a non-parent influenced my view of what would constitute a normative style of parenting and what may be a product of a parent's experience of baby loss. Very little research has been conducted exploring normative levels of parental

worry regarding their children, though Fisak et al. (2012) and Stickler et al. (1991) note that a level of parental worry can be assumed. Therefore, I used my clinical and personal experiences alongside consultation with my research supervisors, both of whom are parents, to consider what would constitute a natural level of worry for parents and what may be implied due to loss.

A strength of this study was the researcher's ability to create an interview environment where couples felt comfortable discussing sensitive and personal experiences. Time was taken in each interview to ensure participants could settle in and make themselves comfortable, for example ensuring they knew they were able to make a cup of tea or answer their children when needed. As the researcher, I drew on clinical skills of active listening and empathy when participants became emotional and ensured they felt supported and not rushed. It felt important during interviews to ensure parents felt able to express and be emotional due to the sensitive nature of the subject. Therefore, when one mother became particularly upset, I did not rush to tell her she could take a break or withdraw. Instead, I slowed the pace, provided reassurance, and contained her emotions, allowing her to come back to her window of tolerance. She went on to tell a rich and powerful story of how she, as a mother, has been impacted by baby loss. If I had immediately offered for the couple to take a break or withdraw, I believe it would have communicated that I was unable to hold the emotion. This would have left participants feeling uncontained and important stories would have been missed. I believe that taking this position as the researcher, alongside the format of using a narrative approach, allowed the participants to produce many rich stories during the interviews. However, the time and word limitations of the current study meant that not all of this data could be used and not all the stories could be shared. As well as considering the stories shared but not heard in the write-up of this research, it is also important to consider the

stories and voices that were not heard in the interviews, due to not participating or not feeling able to share in the interview context.

I believe that interviewing couples conjointly was a strength of the current research. Societal discourse places fathers in a secondary position as storytellers of parenthood, and the experience of baby loss may have caused some male voices to be silenced. Prior to conducting the interviews, I wondered whether interviewing couples conjointly may further contribute to this silencing of the male voice. However, it felt as though interviewing couples conjointly added to the richness of the stories told and often partners facilitated the sharing of their partner's stories. For example, partners sharing stories of one another contributed to the revealing of both fathers' and mothers' more personal stories of parenting in the context of prior perinatal loss. Therefore, joint interviews allowed gender differences to be enacted and witnessed and facilitated the sharing of more personal stories from both mothers and fathers. Couples appeared to co-construct their narrative within the interview by prompting further memories and stories from one another. Interviewing couples together also allowed the stories to be shared more naturally as they talked amongst each other, rather than relying on researcher prompts. The storytelling was done in a more naturalistic setting as the couples exist and parent as a dyad and this is how their family stories would be typically shared.

Due to the sensitive nature of the interview topic, it may have been harder for parents to share their stories via video call, without meeting me in person. Often a sense of safety is required before people feel able to share personal stories, and this can be harder to gauge when meeting someone online. However, I believe that this was counterbalanced by a number of factors including the researcher's experience as a clinician in making people feel at ease and by being able to participate as a couple. Furthermore, 14 of the 15 couples participated from their homes, and so likely felt comfortable and primed to a mindset where

familial storytelling felt natural and accessible. This is opposed to participating in an unfamiliar location as would have likely been the case if the interviews were to be conducted in person.

A limitation of the current study may be the lack of diversity within the sample. The majority of participants were able-bodied and of a white ethnic background. Information on education, class and socioeconomic status were not collected. These parents may have different experiences from parents that fall within other, minoritised groups. Given more time, the study could have made efforts to recruit a more diverse sample. However, as a novel study, the priority in recruiting was to attain a sample with a diversity of experience, rather than demographics. Couples who share similar demographics may have very different experiences of baby loss and parenting and even couples with similar experiences, may interpret or be impacted by these in very different ways. A report conducted in the UK showed that baby loss rates differ based on factors including socioeconomic status and ethnicity (Draper et al., 2020). It was documented that stillbirth and neonatal mortality rates increased with deprivation across all ethnic groups. If the research were to be repeated, it may be helpful to use Diaz's (2012) suggestions to specifically encourage participation from minoritised groups. This advice includes establishing trusting relationships with communities of minoritised groups and working to identify and problem-solve barriers to participation on an individual level.

Conducting interviews online facilitated access to participation from a wider geographically located sample. This also allowed parents to engage without finding childcare and often at times that would have been hard to facilitate in person, such as late in the evening, after their children went to bed. If interviews had been limited to the researcher's working hours, parents may have had to miss their work to participate. Similarly, if

interviews were in person, couples may have needed to drive or take public transport to the interview location, both costing time and money. The ability to participate from home and outside of working hours likely promoted access by couples from a wider range of socioeconomic status households.

As the majority of recruitment was done through a baby loss charity, the included population may be more likely to be couples that have accessed support of some kind and therefore may feel more able to share their stories than others who have not had access to support. Conversely, seeking support may indicate that they were more impacted than parents who did not seek support. The willingness of the participants to take part and share their stories may also be indicative of a certain type of person or style of parenting or grieving that may not be shared by others who feel less inclined to participate in research. For example, couples who show a willingness to share their experiences in research may be more likely to find the continuation of their relationship with their baby who died through storytelling more useful than those who are less inclined to share their stories. Those people less inclined to share may find other ways of connecting with their baby who died.

Though the aim of the research interview was focused on the impact of baby loss on subsequent parenting and this was made clear in the participant information sheet, participants often told stories relating to their experience of loss. Though this was often necessary to provide a context for their current narrative of parenthood, participants struggled at times to stay focused on the impact of the loss on their current parenting. This is likely due to the disenfranchised nature of baby loss, meaning it is not a topic that parents feel readily able to discuss. Therefore, the research interview likely set up a possibly rare opportunity to connect with and remember their baby that died. In line with the findings, this likely increased the possibility of parents using the interview time to connect with the baby that

died, rather than focusing on the surviving child. If the research were to be revisited, an alternative approach may be to have two interview phases, one of which the couple provides their story of loss and establishes the context for the second part of the interview where participants are asked to focus on the impact of their loss on subsequent parenting. However, as per the current findings, it may be that this narrative style is indicative of parents' ongoing process of cycling between connecting with their baby that died and then connecting again to their surviving children.

It is important also to consider the impact of the researcher. As Reissman (2005) suggests, stories are co-constructed with the audience they are shared with. It is therefore important to reflect on how the participants perceived the researcher and how the assumptions they made may have impacted the stories they chose to share or not to share. I did not share any personal details of my family experience with baby loss with participants and instead only shared limited information about my role as a researcher and trainee clinical psychologist when asked. As a lone female researcher, mothers may have felt more of an affinity with the researcher and thus more able to share their stories. However, it did not appear that the researcher limited the contribution of fathers to the co-construction of the couple's narratives in such a way.

As well as the immediate context of the research interview, it feels important to recognise the national and global context in which the research was conducted that may have influenced the findings. The interviews were conducted from November 2022 to June 2023. Two years prior to this, on 11th March 2020, the World Health Organisation announced the novel coronavirus outbreak as a global pandemic (GOV.UK, 2022). This marked the beginning of a series of national and global events such as lockdowns, vaccinations, behavioural restrictions and a global increase in fear regarding health and safety. It is likely

that to varying degrees, all couples interviewed will have been impacted by these events. Increased fear globally, reduced access to healthcare and uncertainty may have contributed to parents' concerns regarding their children's health and therefore increased risk consciousness. Yassa et al. (2020) found that the pandemic caused women in their third trimester of pregnancy to experience constant thoughts of themselves contracting COVID-19 and also held concerns regarding their baby becoming infected. Some of the parents interviewed explained that they had been pregnant during the pandemic which meant they were able to conceal their pregnancy from others and spend more time as a family following the birth of their rainbow baby. Oskovi-Kaplan et al. (2020) found that mothers whose third trimester overlapped with lockdowns were at increased risk of postpartum depression as compared to before the pandemic. However, they found no difference in maternal bonding status, as measured by the Maternal Attachment Inventory. Therefore, though lockdowns may have influenced a continued desire to prioritise protected time as a nuclear family and influenced the parent-child relationship in this way, it is not definite that it impacted parent-child bonding.

4.5 Suggestions for Future Research

Further research exploring the impact of perinatal loss on subsequent parenting in a more diverse population would be beneficial as it is known that different groups, specifically parents from lower socioeconomic groups and racialised backgrounds, are disproportionately impacted by baby loss (Draper et al., 2020). The experiences of non-heteronormative parents, including same-sex relationships should be explored as the difference in familial structure may influence the meaning parents attach to baby loss and the arrival of subsequent children. Exploring the impact of baby loss on subsequent parenting in different demographic groups would be beneficial in tailoring clinical implications for different families.

The literature review revealed that baby loss can impact people's faith. The current study did not explore the impact of faith on parenting children born subsequent to loss. This may be due to the demographic included in the current study. However, it may be of interest for future research to explore whether faith may be a supportive factor in raising children born subsequent to loss. It may also be of interest to explore whether this can affect the meaning that parents make of the arrival of their children born after baby loss. This could then be considered alongside therapeutic support for families parenting after baby loss.

Future research exploring how the narrative features and types described by parents are experienced by the children born subsequent to baby loss may be beneficial. This could identify whether any support is needed for these children. It may be of particular interest to explore how children make meaning of their parents' ongoing relationship with their missing sibling and how they themselves relate to their missing sibling. It may also be helpful to explore how children perceive their parent's gratitude towards them, whether this is wholly positive or creates a sense of pressure in the children to live up to high expectations. It would be of equal interest to better understand whether these children are also more risk conscious, or whether parents' efforts to counterbalance their risk consciousness means that their children are unaffected by this.

Though the chapter remaining open appeared to be a positive process for parents and this would be supported by Michael White's (1988) work in narrative therapy, further exploration of this would be helpful. For example, keeping the chapter of baby loss open may also mean parents remain more susceptible to emotional triggers of baby loss, as they are living closer to the pain. This may help to develop Michael White's (1988) therapeutic framework more specifically for parents who have experienced baby loss.

It could be helpful to conduct a similar study comparing parents who have, and have not, accessed support for their grief. By exploring whether their experiences of parenting differ, more could be learned about the importance of bereavement support following baby loss. If, for example, parents who have not accessed support experience more challenges when parenting subsequent children, this could enhance the rationale for the importance of services providing support for couples following baby loss. Research shows that couples look to one another for support following baby loss and the literature review revealed that when this is done well, support within the couple is very important in coping with baby loss (Hooghe et al., 2012; Kamm & Vandenberg, 2001; Wing et al., 2001). Therefore, it may also be helpful to explore the experiences of parents who are separated or divorced and raising a child subsequent to loss. These parents may present a greater need for clinical support.

4.6 Clinical Implications

As discussed in the introduction and demonstrated in the literature review, research shows that couples will often go on to have children following perinatal loss. It is therefore important to consider the needs of this population within clinical healthcare settings. Mills et al. (2016) recommended that specialist care should be provided during subsequent pregnancies to mitigate the associated risks of poor health outcomes. The National Bereavement Care Pathway (NBCP) provides guidance for healthcare professionals in delivering compassionate and consistent care to parents affected by pregnancy loss during subsequent pregnancies (NBCP, 2024). However, research has shown that women may have negative experiences during subsequent pregnancies due to unreliable access to specialist services or professionals equipped to provide specialist emotional and psychological support, miscommunications, and needing to re-tell their story of baby loss multiple times (Mills et al., 2016; Heazell et al., 2016). There is even less support beyond the point of a subsequent birth. Therefore, while there have been advances in service provision and policy

development, there remains a need for further investment to improve access to specialist support services to address the complex psychological needs of individuals beyond experiencing a rainbow pregnancy. The unexpectedly high number of potential participants who volunteered to take part in the recruitment phase potentially highlights this unmet need.

Prior to the birth of subsequent children, it may be helpful for clinicians working therapeutically with parents soon after baby loss to consider the future of these families. Having an awareness of what they may experience after having subsequent children would be helpful. This can then be spoken about and shared with parents wanting to go on to have more children. Speaking about what to expect may benefit parents in preparing them for parenting after loss and normalising their experiences.

The current findings build on Donegan et al.'s (2023) suggestion that there should be established care pathways specific to caring for women and their partners in a pregnancy subsequent to a perinatal loss. The current findings suggest that this pathway should incorporate the option of continuing support following the birth of a child subsequent to perinatal loss. Again, this should be offered to both mothers and their partners as both parents can be affected by baby loss. This would mean services developing beyond the traditional offer of support targeted only to mothers.

As there appears to be a paucity of services or pathways established to specifically support couples parenting after loss, if these parents struggle, they are likely to access and be seen in more general mental health services. Therefore, the clinician they meet may not have knowledge specific to baby loss and how this impacts parents' future pregnancies and parenting. It is therefore important to develop guidelines for clinicians to access when they meet this population, this could also be delivered as training to staff in primary care mental health services such as Increasing Access to Psychological Therapies (IAPT) services.

Guidance should include that when working therapeutically with these parents, it is important

to consider how risk consciousness may be impacting their lives. It will also be important to pay attention to parents' public stories whilst also considering that they may have a different personal story which may vary according to the parents' gender. These personal stories may be more easily accessed when working systemically with the parents as a couple.

Alternatively, personal narratives may be shared when a rapport has been established with the clinician. It is important to provide a non-judgemental, safe space for parents to feel able to bring and articulate their personal stories. Clinical services should look beyond offering individual therapies and ensure parents have the option of accessing support as a couple.

When working with fathers within this population, it is helpful to be curious about how they understand their role in the family following baby loss. If this is one of support, they may need encouragement to access their own feelings of grief and be given permission to make space for this. This may feel uncomfortable or disruptive for fathers at first. Taking time to consider the influence of wider societal discourses on fathers' stories may be beneficial during the process of formulation.

Similarly, considering wider societal narratives when formulating with mothers would also be helpful due to the impact of these on feelings of helplessness and self-blame. It may be helpful to develop a screening tool to aid clinicians in identifying mothers who may be struggling to see themselves occupying the role of mother. These mothers may benefit from additional support to feel aligned with their parenting role and feel more confident in their ability to connect with and protect their children. It is likely that this screening tool would be most beneficial if given a period of time after the birth of their subsequent child. This would allow for the mother to settle into her role naturally as a period of disruption and unknowing may be expected for any new mother, especially in the context of having prior perinatal loss. The current findings suggest that for many mothers, this disrupted sense of being a mother will correct itself. However, for some, additional support to address this may be beneficial.

This support may also indirectly benefit the family system as the mothers may become less reliant on the father for support and it may facilitate the development of a secure mother-child attachment. It would be helpful to explore and consider feelings of responsibility when working with mothers raising children after perinatal loss in therapeutic settings.

My findings in combination with the findings of the literature view and continuing bonds models of grief such as Michael White's work of 'saying hello' suggest that a space for parents to share stories of their babies that have died may be useful. This could be in the format of a support group facilitated by a professional trained in narrative therapy. This could also be done in the form of an online support forum where parents are invited to share and document their stories with other parents. A family workshop where families are able to co-construct their stories together, with their rainbow children may be useful. This could be led by someone trained in narrative therapy, using a similar format to previous workshops run for the Tree of Life (Hughes, 2014). This could help parents to navigate how they integrate their stories of their baby that died into their evolving family narrative with the children born subsequently. Similarly, this may help parents to support their children with their own feelings around the loss of their sibling, especially as they grow up and their relationship to their sibling develops. Parents may need support in navigating any stage of this process. Peer support forums may be a useful place for parents to meet and support each other with this. In accordance with keeping the chapter of baby loss open in the context of a growing family, Michael White's (1988) narrative method of 'saying hello' may be adapted and used with families who have experienced perinatal loss. This may facilitate the process of keeping the chapter open and offer guidance to parents on how to do this as a family.

Though further research is required on the impact of the current findings on the children born subsequent to loss, it is likely that support would be beneficial for these children. Research shows that increased parental anxiety can increase the likelihood of

children's anxiety. It is also unclear how the rainbow children may make sense of their parents keeping the chapter of baby loss open and how they incorporate this into their sense of self.

4.7 Dissemination

This research will be presented within the University of Essex to staff and students on the Doctorate in Clinical Psychology course. This will be done in the form of a poster presentation.

The research will be disseminated to all of the participants of the research as this was offered and requested by all participants. This research will also be shared with the charity, Sands. With Sands, I have discussed creating a summarised version of the research in poster or leaflet format for easier dissemination to parents. Various clinical professionals working in the area of baby loss have expressed interest in reading the final research when I spoke with them during the initial phases of the research planning process. These professionals have been clinical psychologists and psychotherapists, but the research could also be disseminated to midwives and GPs to inform clinical practice. For example, if they see a parent with prior, known experiences of perinatal loss, they may need to explore additional support options following the birth of subsequent children. I plan to submit the research for publication in relevant journals that are read by professionals. Examples of such journals may be 'BMC Pregnancy and Childbirth', 'Journal of Health Visiting', 'Journal of Productive and Infant Psychology,' and 'Journal of Obstetrics and Gynaecology'.

It is hoped that this research may inform service providers and policymakers in order to provide a more person-centred approach, based on parents' own narratives. Maternal mental health services that are able to work with mothers outside of the perinatal period are currently in development in Norfolk and Essex. It may be useful to inform these services of results as

they may be a suitable service provider to support parents following the birth of a child subsequent to perinatal loss. By providing narratives from couples, rather than just mothers, I hope this research encourages more inclusivity for fathers and partners in perinatal service provision.

As well as hoping that this research will prompt professional reflection and inform clinical practice, it is also hoped that this research will prompt further research in the area.

4.8 Reflexivity

This doctoral research project has been a long journey of personal, academic and professional growth and reflection. My personal experience alongside my clinical work with bereaved families has remained a consistent motivating factor to keep going with the research project. Conducting this research has led me to many inspiring and insightful conversations with many people with personal and professional experiences of perinatal loss and being or having a rainbow baby. This has developed my thinking in analysing and writing the research but also contributed to a journey of self-reflexivity considering what being a rainbow child means for me.

Though this doctoral research project is coming to an end, my research journey continues as I hope to condense my findings for publication and share these with clinicians working in relevant areas. As this chapter closes, I feel grateful for the rich stories shared with me by the participating couples. I also feel apprehensive as to how my representations of their stories may be received. Though it is impossible to include all the rich stories shared with me by these couples, I hope I have been able to do them some justice and that they feel a resonance with my findings. I hope this research sheds some light on the lived stories of bereaved parents raising children and in doing so, may contribute to helping families with

similar experiences in the future by building on professionals' understanding of their experiences and perspectives.

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6. Appendices

Appendix A. Summary of Articles Included for Systematic Review

Paper	Setting	Data collection	Study aim
Hasui & Kitamura (2004)	Recruited via Sudden Infant Death Syndrome (SIDS) Family Association Japan, Japan.	Interviews. Parents who experienced infant loss (38).	To examine aggression and guilt in bereaved family members.
Abboud & Liamputtong (2005)	Recruited via snowball technique and a GP, Australia.	Interviews. Couples from ethnic backgrounds who experienced miscarriage (6).	Exploring the experiences of couples following miscarriage.
Gudmundsdottir & Chesla (2006)	Recruited via support groups, bereavement nurses and advertisements, USA	Interviews. Families of children who died suddenly and unexpectedly. Family members (15) of 7 families (comprised of mothers, fathers and 1 adult sister).	To understand habits and practices developed by families bereaved from the sudden and unexpected loss of their children.

Cacciatore et al. (2008)	Recruited via two online parental support organisations, USA.	Discussion group. Couples who experienced stillbirth (16).	To explore how bereaved parents perceive and cope with the death of their baby and how this affects them both individually and as a couple.
Hamama-Raz (2010)	Recruited via snowball technique within the religious, Jewish sector, Palestine.	Interviews. Parents who experienced spontaneous abortion between the 10 th and 18 th week of pregnancy. Couples (5).	To examine the meaning of abortion in the religious Jewish sector on both the individual and the couple levels.
Lang et al. (2011)	Recruited via Montreal university hospitals, Canada.	Interviews. Parents that lost their child perinatally or within the first month of life. Couples (13).	To explore sources of ambiguity and disenfranchised grief related to perinatal loss.
Jones-Peebles (2012)	Recruited via social media, USA.	Interviews. Parents who experienced perinatal loss. Couples (5).	To explore the impact of perinatal loss on male partners.

Hooghe et al. (2012)	Hospital department of paediatric oncology, Belgium.	Case study. Parents that lost their child at 6 months old. Couple (1).	To gain a better understanding of the oscillating process of confronting and avoiding the pain of loss.
Avelin et al. (2013)	Recruited via 5 hospitals, Sweden.	Questionnaires. Parents who experienced stillbirth. Mothers (33), fathers (22).	To explore the impact of grief on couple's relationships following stillbirth.
Dickerson (2016)	Recruited via perinatal loss and SIDS support groups, USA.	Interviews. Parents who have lost a child by miscarriage or stillbirth. Mothers (7), fathers (1).	To explore the impact of perinatal loss among adolescent parents.
Brierly (2017)	Recruited via online pregnancy loss organizations, Facebook pregnancy loss groups, and Women's Health Centres within the Boston-Metro West area, USA.	Interviews. Parents who experienced a late-term pregnancy loss. Couples (9).	Examining couples' experiences grieving a pregnancy loss on Facebook.

Kofod & Brinkmann (2017)	Private support organization for bereaved parents following infant loss, Denmark.	Interviews. Parents who experienced infant loss. Couples (6), mother only (1).	To explore the normativity of grief.
Nuzum et al. (2018)	Tertiary university maternity hospital, Ireland.	Interviews. Parents who lost a child by stillbirth. Mothers (12), fathers (5).	To explore the experiences and impact of stillbirth of bereaved parents.
Currie et al. (2019)	Recruited via NICU bereavement program, USA	Parents who experienced the death of an infant in a NICU.	To explore parent bereavement and coping experiences following infant death in the NICU.
Clark et al. (2021)	Midwestern, Level IV NICU.	Interviews. Parents who lost an infant on a neonatal intensive care unit (NICU). Mothers (29), fathers (16).	To explore parent perceptions of the impacts of their infant's death in the NICU.
King et al. (2021)	Recruited via social media and national support groups, USA.	Interviews. Parents who lost a child by stillbirth. Couples (8).	To explore parents experiences of stillbirth from the time they suspected something was

			wrong to beyond leaving the hospital.
Tanacioğlu-Aydın & Erdur-Baker (2022)	Recruited via purposive sampling and using social media, Turkey.	Interviews. Couples who experienced pregnancy loss (10).	To explore how Turkish sociocultural factors impact grief experiences following prenatal loss.
Kristvik (2022)	Parents recruited from 3 hospitals in Norway.	Interviews. Parents who lost a child by stillbirth. Couples (18).	To understand bereaved parents' unique perspectives on what they perceived to be helpful or harmful in the mourning process after losing a child in stillbirth.
Steele (2023)	Recruited via social media, a local perinatal bereavement coordinator, and via	Interviews. Parents who experienced perinatal loss. Fathers (20), mothers (9).	To better understand parents' experiences of returning to work after perinatal loss

snowball sampling
at the end of
interviews, USA.

Appendix B. Recruitment Flyer



University of Essex

Participants wanted

Have you had a rainbow baby?

If you feel your loss impacted how you parent your rainbow baby, I would love to hear from you and your partner.



The aim of my research is to explore couple's experiences of parenting a child or children following the loss of a baby. I want to give voice to these couples and bring dads and partners into the research.

GET IN TOUCH:

GEORGIA SMITH
(Trainee Clinical Psychologist)

██████████@nhs.net



ERAMS Reference Number: ETH2122-1292

Appendix C. Participant Information Sheet



Participant Information Sheet

Title of Research: Couple's experiences of parenting a pre-adolescent child following perinatal loss

My name is Georgia Smith and I am a Trainee Clinical Psychologist undertaking my Clinical Psychology Doctorate at the University of Essex. I would like to invite you to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve.

Please take time to read the following information carefully.

What is the purpose of the study?

The purpose of the research study is to better understand the experiences of couples who have experienced baby loss and then gone on to have a subsequent child, sometimes known as a rainbow baby. The research will focus on the couple's experiences following the birth of their rainbow baby from infancy to pre-adolescence, reflecting on how they feel their loss has impacted their parenting and relationship with their child.

Research shows that baby loss can impact parents in various different ways; the current research aims to understand how this influences parenting of subsequent children. I would like to stress that this is non-judgemental research. There are no right or wrong answers, the aim is to better understand couple's experiences and what forms of support would be most valuable for bereaved families following the birth of subsequent children.

The current research project is being run in relation to a Clinical Psychology Doctoral programme, and the research will be written to form my thesis. The results of the research are expected to be published following completion and disseminated to aid and advise current practice within perinatal healthcare.

Why have I been invited to participate?

You have been invited to participate as you experienced the loss of a baby which you feel has influenced the way you parent your subsequent child or children. The research aims to interview around 15 couples to gain a rich and meaningful picture of the effect of baby loss on subsequent parenting.

Do I have to take part?

Participating in this research project is completely voluntary. It is up to you and your partner to decide whether or not you wish to take part in this research study. If you do decide to take part, you will be asked to provide written consent. You are free to withdraw at any time, without giving a reason and without penalty.



If you should wish to withdraw, you can contact the researcher directly. If you choose to withdraw prior to analysis, expected to be started in January 2023, your data and responses can be removed and destroyed. However, if you chose to withdraw following analysis your information will be unable to be revoked as it will not be possible to retrieve as it will have been anonymised. Withdrawal of data is therefore possible up to the point of anonymisation.

What will happen to me if I take part?

If you chose to take part, you and your partner will be invited to take part in a joint interview over videoconferencing software. Prior to the interview, you will be asked to complete a Consent Form and a Demographic Information Questionnaire.

The interview will be conducted by Georgia Smith and will contain questions which enable you to reflect on your experiences as parents of a child or children subsequent to baby loss(es). The interviewer may ask additional prompt questions to assist with your answers if expansion is necessary. The interview is expected to last from 60-90 minutes. You will be able to take breaks whenever necessary and your wellbeing and comfort is of paramount importance. Should you wish to not answer a question, this is also permitted with no consequence and the researcher will move onto the next question. Demographic information will also be collected at the start of the semi-structured interview.

Following the interview, you will be allowed to ask any questions you may have about the research or the interview. The researcher will provide a verbal debrief to check how you are feeling, and to ensure you are not distressed by the content.

Should the research cause you distress, the Signposting Information Sheet will guide you to appropriate and relevant services. Your wellbeing is paramount.

It is expected that data will be collected in one session, however if you should wish to complete the interview over two sessions, this may be able to be facilitated. The semi-structured interviews will be audio recorded to enable transcription and analysis. These recordings will only be accessed by the researcher and will be recorded using an encrypted Dictaphone.

Data will be anonymised, and it will not be possible to identify yourself following data analysis. Direct quotes may be used in analysis and in the results write-up, but again it will not be possible to identify participants from these extracts.

What are the possible disadvantages and risks of taking part?

It is not expected that there will be any risk or disadvantage to participating in the current research study. However, it may cause distress to be asked to think about the impact of your grief in a formal research setting. The questions are designed to be open to ensure honest reflections, but this could give way to information being discussed which could be potentially difficult in nature.



Alongside this, reflecting on experiences can be difficult for individuals and trigger unexpected emotions. The researcher is trained to ensure individuals feel comfortable, safe, and will be able to signpost if they experience any additional distress following the interview.

The research will be kept confidential, meaning that the participants will be unable to be identified throughout and following the interview. However, if any information received indicates risk of harm to either of the participants, or others then confidentiality may need to be breached in order to ensure safety. If this were to occur, wherever possible a discussion would be conducted with the participants prior to this occurring.

What are the possible benefits of taking part?

Whilst there are no overt benefits to participating in the current research for the participant, it is felt that it is highly important to research this topic to further our current understanding of the impact of baby loss(es). Participation would be contributing to research which aims to provide rationale for increased support to be available for parents following the birth of a child or children following baby loss(es).

The research aims to have the voices and experiences of parents who have gone through baby loss heard so that they can be reflected in perinatal research and healthcare practices.

Alongside this, it may be beneficial for individuals to reflect on their experiences of parenting in order to develop their own understanding of their experiences. All participants who take part in the research will be asked and offered an opportunity to have a copy of the final paper to help with their understanding.

What information will be collected?

Information about how you feel your baby loss(es) has influenced your parenting of and relationship with your subsequent baby or babies and what you feel would have been helpful for you. This information will be collected from the semi-structured interview which will be transcribed by the primary researcher. Audio recordings will only be heard by the lead researcher. Shortly after transcription, all data will be anonymised. The data will be analysed by the primary researcher and themes will be identified.

Will my information be kept confidential?

Information provided by participants will be kept confidential within legal limitations during and after the research study. If during the course of the research, a participant will disclose information that leads the primary researcher to believe that they or others are at risk of harm, the primary researcher has a duty of care to inform an appropriate authority. If this were to occur, the primary researcher would always attempt to discuss this first with the participant(s).

Information and data will be kept secure utilising password protected documents, the dictaphone will be encrypted, requiring a passcode to listen to the files.



Only the primary researcher will have access to the original data collected through the original interviews. The research team will have access to the transcripts in case any distress arises and as these will be required to be double coded to ensure integrity of analysis. Shortly after transcription, prior to analysis, information will be anonymised, and participants will not be identifiable.

Paper consent forms will be scanned, and the paper copies will be destroyed as per the University of Essex' policy. The scanned copies and online copies will be kept within a secure file and password protected. The data will be stored for a period of ten years post completion of the project adhering to the University's Research Data Management Policy.

What should I do if I want to take part?

Should you wish to take part in the current research study, please contact Georgia Smith via email at [REDACTED]. Recruitment for the project is expected to be completed by January 2023, therefore please enquire prior to this date. It may be possible this deadline would be extended if additional participants are required.

What will happen to the results of the research study?

It is hoped that the results of the study will be published into a journal article and will therefore, be available in the public domain. As previously stated, you will not be identifiable from the results of the research and all published and reported findings will be anonymised.

The results of the research will also be used in the primary researchers' (Georgia Smith) thesis which again will be accessible by the public and stored in the University of Essex library. This will be stored online in PDF format.

Following completion of the research, a copy of the findings will be available to each participant and if requested, these can be emailed as PDF to the participants.

Who is funding the research?

The research is funded by the University of Essex, Doctoral Clinical Psychology Programme. There are no financial gains to the University or the researcher from this research project.

Who has reviewed the study?

The study will be reviewed and approved by Ethics Sub Committee 2. Should you require further information please contact them on [REDACTED].

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the primary researcher, Georgia Smith, using the contact details below.



If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the primary researcher, please contact the lead supervisor, Dr John Day, using the contact details below.

If you are not satisfied with this, please contact the University's Research Governance and Planning Manager, Sarah Manning Press ([REDACTED]). Please quote the ERAMS number found at the foot of this page.

Research Team

Primary Researcher: Georgia Smith (Trainee Clinical Psychologist) department of Health and Social Care at the University of Essex. **Email:** [REDACTED]

Lead Supervisor: Dr John Day (Lecturer) department of Health and Social Care at the University of Essex. **Email:** [REDACTED]

Secondary Supervisor: Dr Richard Pratt (Lecturer) department of Health and Social Care at the University of Essex. **Email:** [REDACTED]

Appendix D. Consent Form



Consent Form

Title of Research: Couple's experiences of parenting a pre-adolescent child following perinatal loss

Research Team: Georgia Smith (Primary Researcher, Trainee Clinical Psychologist), Dr John Day (Lead supervisor, Lecturer), Dr Richard Pratt (Secondary supervisor, Lecturer)

Please both read the following statements carefully and mark each box if you agree.

We have read and understood the Participant Information Sheet for the above study. We have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily.

We understand that our participation is voluntary, and we are able to withdraw from the research at any time, without giving any reason and without penalty. We understand that any data collected up to the point of my withdrawal may be destroyed unless it has already been anonymised for analysis, at which point it will no longer be possible to identify.

We understand that the identifiable data provided will be securely stored and accessible only to the research team, and that confidentiality will be maintained. The only exception to this being if the lead researcher believes you, or someone around you, is at risk of harm.

We understand that any identifiable information will be anonymised during transcription and therefore, though quotes may be used in the final write up, these will be anonymised and not personally identifiable.

We understand that the data collected will be used to support other research in the future, and may be shared anonymously with other researchers. The research is expected to be published following completion.

We agree to take part in the above research.

First Participant Name	Date	First Participant Signature
-----	-----	-----
Second Participant Name	Date	Second Participant Signature
-----	-----	-----
Researcher Name	Date	Researcher Signature
-----	-----	-----

Contact details for primary researcher: Georgia Smith (Trainee Clinical Psychologist) department of Health and Social Care at the University of Essex. **Email:** [REDACTED]

Appendix E. Signposting Information Sheet



Signposting Information Sheet

There are various organisations set up to support parents who have experienced baby loss. If you feel you or your partner need support, please reach out.

Bereavement support after the death of a baby

Sands

Sands is the leading stillbirth and neonatal death charity in the UK. Sands exists to reduce the number of babies dying and to ensure that anyone affected by the death of a baby receives the best possible care and support for as long as they need it.

Helpline: 0808 164 3332

Email: helpline@sands.org.uk

Website: <https://www.sands.org.uk/support-you>

Bereavement support app: <https://www.sands.org.uk/app>

A Child of Mine – Help for Bereaved Parents

Providing accurate, up to date practical information and guidance after the death of a child. Ensuring professional bereavement services are improved through the experience of other bereaved families. Designing and delivering more direct services to families after the death of a child, including financial assistance, support and practical advice.

Helpline on 07803 751229 from 9:00am – 5:00pm

Telephone: 01785 283 434

Email: hello@achildofmine.org.uk

Website: www.achildofmine.org.uk

Antenatal Results and Choices (ARC)

ARC offers non-directive information and support to parents before, during and after antenatal screening; when they are told their baby has an anomaly; when they are making difficult decisions about continuing with or ending a pregnancy, and when they are coping



with complex and painful issues after making a decision, including bereavement. They offer a Helpline, support network and literature for parents, families and professionals.

Helpline: 0845 077 2290 or 0207 713 7486

Monday-Friday, from 10:00am until 5:30pm

Email: info@arc-uk.org

Website: www.arc-uk.org

At A Loss

An online site where users can search for the most suitable support throughout UK.

Website: <http://www.ataloss.org/find-support/search>

Care for the Family

Care for the Family provides parent support, family support and bereavement support. This is a family orientated organisation, promoting strong family life, and help with any difficulties within a family. It has a Christian compassion ethos. They run parenting courses throughout the UK

Telephone: 029 2081 0800

Email: mail@cff.org.uk

Website: www.careforthefamily.org.uk

Child Bereavement UK – CBUK

Child Bereavement UK supports families and educates professionals when a child of any age has died or is dying and when a child is bereaved.

Child Bereavement UK offers support for adults and bereaved children and young people up to the age of 25.

Offers free face to face bereavement support in these areas: Buckinghamshire, Cheshire, Cumbria, Glasgow, Leeds, Milton Keynes, East London, West London.



National Helpline: 0800 02 888 40

Monday to Friday, from 9:00am – 5:0pm

Email: support@childbereavementuk.org

Live chat via website

Website: www.childbereavementuk.org

The Child Death Helpline

A dedicated helpline that offers support to anyone affected by the death of a child of any age, under any circumstances, however recent or long ago.

Helpline: Freephone 0800 282 986 or 0808 800 6019

Monday to Friday 10am to 1pm, Tuesdays 1pm to 4pm, Wednesdays 1pm to 4pm

Every evening 7pm to 10pm

Email: contact@childdeathhelpline.org

Website: <http://childdeathhelpline.org.uk>

Also offers free interpretation for languages other than English on the phone.

The Compassionate Friends

An organisation of bereaved parents and their families offering understanding, support and encouragement to others after the death of a child or children.

National Helpline: 0345 123 2304 (Daily 10:00am-4:00pm, 7:00pm-10:00pm)

Northern Ireland Helpline: 0288 77 88 016 (Daily 10:00am-4:00pm, 7:00pm-9:30pm)

Website: www.tcf.org.uk

Email: helpline@tcf.org.uk



Cruse Bereavement Care

Cruse Bereavement Care offers free support for people bereaved by death, in any way, whatever their age, nationality or belief. Help includes 1-to-1 bereavement support, bereavement support groups and advice or information on practical matters and a helpline.

Cruse has a dedicated website for young people: www.hopeagain.org.uk A special feature of this site is a message board where young people can share their experiences and receive replies from trained young supporters.

Helpline: 0808 808 1677

Email: helpline@cruse.org.uk or info@cruse.org.uk

Website: www.cruse.org.uk

Lullaby Trust

The Lullaby Trust provides expert advice on safer sleep for babies, emotional support for bereaved families and raises awareness of Sudden Infant Death Syndrome (SIDS).

Bereavement Support Helpline: 0808 802 6868

Info & advice: 0808 802 6869

Open Monday – Friday 10:00am – 5:00pm

Weekends and Public Holidays 6:00pm – 10:00pm

Email: support@lullabytrust.org.uk

Website: www.lullabytrust.org.uk

Miscarriage Association

The Miscarriage Association offers support and information to anyone affected by the loss of a baby in early pregnancy. They also raise awareness of miscarriage and promote good practice in medical care. They provide a network of support groups and telephone contacts throughout the UK.

Helpline: 01924 200799



Monday–Friday, from 9.00am – 4.00pm

Email: info@miscarriageassociation.org.uk

Website: <https://www.miscarriageassociation.org.uk/>

Petals

Petals is the Baby Loss Counselling Charity. They provide free-of-charge specialist counselling to support the mental health of women, men and couples who experience pregnancy or baby loss. Their counsellors provide a safe space to guide parents through the grief and trauma of their devastating experience to a place of reconciliation and hope for the future.

Petals' national online video counselling service provides psychological support to people across the UK, and in some areas they also provide counselling in person, in partnership with hospital Trusts.

Tel (counselling queries): **0300 688 0068** (local charges apply)

Email: counselling@petalscharity.org

Website: www.petalscharity.org

Saying Goodbye

Part of the Mariposa Trust. Saying Goodbye provides Cathedral remembrance services for anyone whose baby has died at any stage of pregnancy, at birth or in infancy.

Telephone: 0845 293 8027

Email: info@sayinggoodbye.org

Website: www.sayinggoodbye.org

Website: www.mariposatrust.org

Admin: office@sayinggoodbye.org



Twins Trust Bereavement Support Group

Twins Trust Bereavement Support Group is for parents who have lost a twin/multiple or both/all twins/multiples. Main website is for support with live twins/multiples so may want to direct them specifically to bereavement area.

The Support Group offers parent to parent support via their [befriending](#) service and via their closed [Facebook bereavement support group](#).

Website: <https://twinstrust.org/bereavement.html>

Email: bereavementsupport@twinstrust.org

The Ectopic Pregnancy Trust

The Ectopic Pregnancy Trust focuses on early pregnancy loss through ectopic pregnancy. This is a charity providing extensive general information and peer support for anyone experiencing the condition.

Website: <https://ectopic.org.uk/>

Email: ept@ectopic.org.uk

Appendix F. Pre Interview Questionnaire



Pre-Interview Questionnaire

The following questions ask about your demographic information.

Partner A

Partner B

Name:	Name:
Age:	Age:
Gender:	Gender:
Ethnicity:	Ethnicity:
Would you describe yourself as having a disability?	Would you describe yourself as having a disability?

The following questions ask about your loss(es) and your current family set up.

At what stage did you lose your baby/babies?

How long ago did you experience your baby loss(es)?

How old is your rainbow baby/babies now?

Do you have any other children? If so, how old are they?

During the interview, how would you like me to refer to your baby/babies? (e.g. names)

Appendix G. Interview Guide

Interview Guide

(60-90 minutes)

Introduction:

- Who I am
- Why am I carrying out this piece of research
- Confidentiality (and exceptions, including child safety concerns)
- Questions?

To do:

- Collect Consent Form
- Collect Pre Interview Questionnaire
- Give Signposting Information Sheet

Are you able to describe how you feel the loss of your baby/babies **name(s) has influenced your parenting of **rainbow baby/babies name(s)**?**

Possible prompt questions:

- *How about when **rainbow baby/babies name(s)** was an infant? At school?*
- *Do you feel you worry more/less than other parents who have not experienced a baby loss?*
- *How do you feel at different milestones for you baby/babies (*rainbow baby/babies and lost sibling(s)*)?*

Are you able to describe how you feel the loss of your baby/babies **name(s) has influenced your relationship with **rainbow baby name(s)**?**

Possible prompt questions:

- *How did it influence your bond with **rainbow baby name(s)**?*
- *Describe how close you are to **rainbow baby name(s)**?*
- *Describe how you feel when you are apart from **rainbow baby name(s)**?*

How do you tell the story of your loss to rainbow baby /others? How do you involve rainbow baby in this story? How does this influence you now?

Ending:

- Is there anything else you think would be helpful for me to know?
- Debrief
- Would you be happy for me to email you to pass on study info to other potential participants?
- Reminder of onward process and signposting information
- Would you like a copy of the research?
- Thank for time and participation

Appendix H. Example Anonymised Transcript

Anonymised Interview Transcript 1
25/11/2022 - John & Carol (J&C)

C: Hiya

R: Hi Carol, hi John, can you see and hear me ok?

C: Yeah, I'm just putting my email on do not disturb

R: Lovely, and lovely to meet you both

J: Yeah you too

R: I will start with introductions so you know a bit more about me and what to expect from today so I am [REDACTED], I'm a trainee clinical psychologist and this research is part of my Doctorate training. I'm doing this research because it's an area I'm interested in and there's really not that much research or support out there for families having a baby after a baby loss.. and I also want to bring Dads and partners into the research because at the moment, it mostly focuses on Mums. Does that all sound ok?

J: Yeah

C: Yeah

R: Great so we have an hour and a half, we may not use all that time or we may need more but either is ok, and if you need any breaks or to take a moment, just let me know and we can do that. I will ask some questions and we can take it from there. Also, you may have noticed the little flashing red dot, I am recording the meeting as we go so that I can transcribe it later. I know you have signed the consent form for me but is this all still ok?

C: No that's fine, I'll just pretend it's not happening

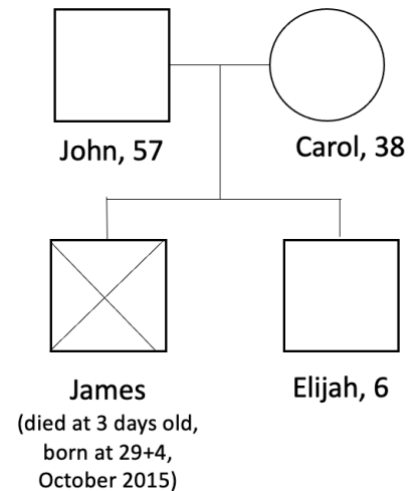
R: So, the recording will only be accessible to me. When I've transcribed it, all names will be taken out and everything will be anonymised so nothing will be identifiable back to you. Do either of you have any questions?

C: No, I don't, I'm just really glad you're doing it. Do you?

J: I don't think so, no.

R: Ok, well shall we get started? My first question is, are you able to describe how you feel the loss of your baby, James, has influenced your parenting of Elijah?

C: Gosh, I said that I'd be really together and.... *(crying)*



R: That's alright, please take your time.

C: Because..(*crying*) Because I know that it affects me more and in a way that I don't think it does you. I think, I just feel so anxious, I have really irrational thoughts that he will die. You know things like he went on a school trip last year and I was convinced that because they were going on the motorway, they would die, which is just ridiculous. And my rational part of my brain is you're only saying this because James died, but then it's really hard to sit with those feelings of 'if he goes on this trip, what if that does happen? And because it was on a motorway and and so I even said to his teacher at the time, she must have thought I was completely mad. I.. I said.. I said I'm really worried that he's going to die because you're going on the motorway and she was really kind, and so then I put him in my group with me. I think I have an issue with umm.. distance. So our school, Elijah's School, is on the same street that we live. So. And we work from home quite a lot, so I feel.. I feel better when he's closer. If he's going somewhere and it's a distance, then I feel a bit umm.. I just feel a bit unsettled. And I think when he went back to nursery and I went back to work after maternity leave, um, I think, it was terrible because our nursery was maybe only about 5 minutes from our house, but initially I could only feel comfortable being in the house. I couldn't go into town, which is maybe about.. Ohh... 10 or 15 minutes away, so I think I've always had an issue with distance, but I can't. You know we've got an office in [REDACTED], so you know I go there sometimes and that's OK. But I think there is a thing about the distance, and like an anxiety sometimes. (*cries again*)

J: I guess we're both super protective of him. I would describe my feelings is that rather than, you know, as not being able to.. you know, leave him and having these dark thoughts about him. I don't have those and but um... and I.. I guess we are... naturally, very protective of him and you know, we don't have a massive support network of people who we are happy to leave him with. Ultimately, so there's only very few people, because, there's actually two.. your mum and his um godmother. That's it isn't it?

C: Mmm

J: Literally those are the only two people that he would go to for a prolonged period.. and certainly for an overnight stay.

C: OK. He's. Yeah. He's only ever had overnights with my mum. But there is.. That doesn't mean that we wouldn't. So you know, most probably 'normal' parents or 'other' parents, you know, after school, one parents running late, might, you know, ring another school mum's and ask can you just pick him up and then can he come to yours for tea? Never in a million years would I ever, not in a million years, never. Oh, I just. No. But we're both social

workers so I think a tiny bit of that is I have my work hat on, in terms of 'I don't know what goes on in that house' but I think that the main part is that he's too precious just to be anywhere.. But yeah, it is a really small.. A very small number of people.

J: Tiny, tiny amount of people that we would honestly leave him with and we've had offers from other people. I think earlier on we had offers from other friends who said, 'oh, you can always leave him with me if you need it'. You know, want a break for a little while and things we've.. we've never used.

These are... sometimes feel a little bit sorry for them really because there was, you know.. And people like Ralph, I'm thinking that, you know, even he said... Umm but yeah.

C: And I wonder if it ever comes across anyone else's mind? As to maybe some of their intricacies behind that, because maybe in some ways it's a maybe a little bit unconscious for us. You know, it might be more so for other people, I'm thinking it's probably quite a hard for them to leave Elijah just umm.. Yeah, that's a big deal in itself, so..

J: Mm, yes, I don't know if people are,

C: Would that ever be on anyone's radar ever? Probably not.

J: I guess it would be for some.

C: Yeah, yeah,

J: Yeah, some people who were there... umm.. very much our support people around the time of James' death.. birth and death. We had some really key people around and about at the time. They for sure are understanding about the reasons why we don't share him about.. share him around, perhaps as much as other parents will.

And I don't know if we if other people would. I don't know if it leads on into whether we spoil him or not. I have sometimes wondered whether we spoil him too.

C: What whether we do or whether people think we do?

J: No, no, whether we actually do.

C: Ohh OK.

J: I don't think we do, we're trying not to. I think we try quite hard not to but.. We also probably do. (*Small laughs*).. Because he's so, you know, he's so precious and umm.. and... our only living child.

R: Yeah, is there anything that prompted that thought that you might spoil him sometimes?

J: I don't know. I don't... I don't know if it goes alongside being protective of a child, you know, if you're super protective of a child, then inevitably you will spoil them to a degree as well. That's the that's the connection I'm thinking of, not specifically to do with like, material things so much as the amount of time we give and in love that is obviously there.

C: He's richer in time by being.

J: Yes,

C: By being our only living child because, you know, we don't have to divide and conquer. So I guess he's rich.. He's richer in that aspect.. Maybe some.. I think sometimes in terms of, you know, in practical sense, like we've got his World Cup sticker book on the table.. you know they're.. they're they're 90 pence for five stickers, it's ridiculous, and you know I do sometimes think there would be an element of... I mean, money's tight anyway, but... it would be tighter if there was another living child and you know, it, it just by that very nature.. um..

J: he gets more.

C: Yeah. And but I think um.. so we never refer to him as an only child. Some other people might do. They might think, oh, you know, he's spoiled because he's an only child. I think I probably have in my mind that I don't want him to.... I'm thinking about... So, we know another little boy who is an only child, and um... I think he's just a handful and I think you can tell and I don't know if it's you're just biased about your own parenting, but I think Elijah's well aware about James. He knows about James. We talk quite regularly, but I would really like to think that we're always quite keen that he doesn't grow up in that spoiled element of getting everything on tap.. everything on demand. So.. Umm, you know.

J: Yeah. It's all relative though, isn't it? Because in comparison with other parents, materially also, he probably gets quite a lot. How many football kits has he got, for example, you know what I mean?

C: Yeah. Yeah. But then, for example, you know, we do buy lots of things from charity shops, you know, the football kits are fake. He's got no idea. But, you know, they're absolutely not the.. Not the official one, shall we say?

You know, when we go in, you know, we've got a tiny charity shop in the next village. When we go in with him, he calls it the toy shop, and he's thrilled to have something. You know, we've been in there before and he's had a pound from my mum, and spent his pound, and, you know, I think for a lot of kids, and maybe it's an age thing as well, you know, there'll come a point where by a pound in the charity shop just won't satisfy him.

For example, from mum, the sticker. I don't even know if we've given him it yet. My mum sent him a pack of stickers in the post on Wednesday. And he was quite rude after his football, and it was he was upset about not being able to have something. So we got home to the stickers and I said to John, 'let's just keep those back for another night', because I thought 'You've just been an absolute monkey.. I'm not then saying, oh, by the way, look what

grandma sent'. But I actually just realized now that we forgot this. We forgot to give him them.

J: So yeah, I think we can be perhaps be spoiling.. Perhaps spoil is the wrong word. Yeah, he's able to invest more out of us... As people, as parents, and I think time wise.

C: I think time wise, we make the decision, money is tighter because John has Thursday and Fridays off, and so that allows him to pick Elijah up from school. Both of those days and you know, it's just you and Elijah from, you know, the moment John gets him from school until after school and I guess.. You know, not all families would do that.

J: Some families would choose to work full time and so not have that Thursday, Friday. But we've always said we're willing to make that financial sacrifice because,

C: yeah, I went part time when he was born. Because that's what we decided. Yeah, that was really important to us, that time and that time would be equally, obviously, as precious to me as to him, and it's over. Obviously preschool. I had him all day on those days, which was amazing. Yeah.

R: Yeah, so we covered a few things there, feelings of anxiety and sometimes feeling very protective. How do you feel like that's changed over time?

C: I mean, I guess from when he first went to nursery and initially, you know initially, for me, not being able to leave the house when he was at nursery in case something happened to then or actually I can pop into town to, I suppose the biggest thing then became probably our office in [REDACTED].

And, you know, when he first went back to nursery, I was very much 'I can't. I can't go to our office in [REDACTED].' It's just that, I mean, bearing in mind, it's, you know, maybe an hour away. So you know, we're not even talking about, you know, a 6 hour drive but yeah.

And I remember that feeling of not being able to leave the house as such a... such a hard.. it was just massive. It was just.. I couldn't possibly. And I think it was about managing the feelings of him being close. But also, and I think I really struggled after having him in, I spoke of feeling safe at home and I quite often only ever felt safe at home. So I, I think that probably leaked into it, into it a little bit as well that I knew he was at nursery. I was really close. But I also felt really safe there, then at home...

And but I think that that has grown and developed overtime. I still think I feel a bit funny about distance so... Yeah, I wouldn't... You know, some people, you know, we know people who've left little ones to go abroad. And so they have a, you know, I don't know, a long weekend in [REDACTED].

You know, I could absolutely not get on a plane, just us two, and leave him, even with my mum.. I just.. I just couldn't. But I know it has improved.

J: Yeah, he can sleep at [REDACTED] now with your mum.

C: Yeah, and that's two hours away.

R: Mm.

J: And so, and you wouldn't have been able to do that at the beginning, when was the first time..? How old was he when he first went?

C: When mum came to our house and then we went. So there's a hotel, literally, a mile up the road from us. We went there. I just felt like if I was there, then we could have some peace. We could relax. But if anything happened, I could be back there and I suppose you (John) were really tolerant of, you know, someone could say, well, you know, this is ridiculous.. We're going up the hill literally.. But I think it did give us a lot in that we just had a night off and.

J: Yeah, and so I think it did get less that way and I suppose we wouldn't do anything that made us feel uncomfortable.

C: And, you know, I mean, Elijah has mentioned sleepovers with school mates. So we know that that time will come. But Oh my gosh. Yeah, it'll be... it'll be on my terms and I guess we are in control of what we feel comfortable with. But it's definitely lessened over time and I'm reflecting now thinking about those earlier days and, you know, and him starting school in reception last year. That was a massive thing.

You know, with me, you know, because he'd been to the same nursery from nine months old until his first year at reception. So I was hugely comfortable there. So to then just transfer all of that trust there within a minute. You know, 'who are you?' That was, that was huge. But, you know, he's in year one now.

J: And we've managed... we've managed that. He's doing fine... He's doing fine.

Pause

R: And how about for you John? Has how you feel changed over time at all or..?

J: It's been roughly the same. I think I'm.. I feel more the same time as when he was a baby... Yeah, I don't.. I don't think I feel like my sort of parenting style has changed from that which it was, really. Except, I suppose, it inevitably changes as children grow.. you do different things, don't you and..

So I used to take him out for naps on my day off in the pram, and I used to do nice long walks at the time, and I knew he would sleep at that time and it was quite a nice time. It was kind of

nice to have, for both of us. Then I was able to do a bit of exercise and he was asleep and things. So you do that kind of thing, don't you?

Whereas now it's he's much more demanding of me, in terms of play. So he wants to play. You can go and play football. He wants to play football now. The ball that

C: He's football mad.

J: Oh yeah, he wants to play all the time. Ohh, and he make things, he's become quite creative and at the moment, he's into making machines and things.

C: things that he thinks are machines and which, in my eyes, is just junk and a mess. It's just a mess of bottles and bits of things.

J: And I'm just.. he wants me to be a part of that.. so, therefore, actually, my parenting is different for me on that level also.

So if James was still with us, then of course, he would be more drawn to involving James. Obviously in his play, I suppose.

R: mm

J: Around the house, he looks to me. Well, both of us to.. to a degree, but perhaps more.. A little bit more.. Maybe because I have the little bit of extra time.. And so I'm his playmate as well as his dad, really.

R: Yeah

J: Umm, I think I'm mindful of that. So I think I'm always mindful that, you know, he hasn't got anybody here to play with as such.

C: And yeah. And we feel that he feels we know he feels that yeah. And he's voiced that before.

J: Yeah. Sometimes he wants to involve people, like inviting them in, and we're a bit nervous about that. For example, like a neighbour.

C: Ohh yeah, yeah. And thingy come and play. Umm well.

J: Maybe another day..

C: Yeah. Another day. And it doesn't help that they're really not.. are somebody we... you know, they're maybe someone we'd deal with through work so it to be.

J: Yeah, we're a bit less inclined. You have the **inaudible** as parents. Yeah, as parents, you have got to be aware of that.

C: He is alone and he's not alone, but he is very aware of James and talks about him all the time. He'll talk about him to his friends in school and things.

J: But he is alone, as a living person, and so inevitably, that will impact on our parenting. But I sometimes wonder.. Whether that's any different than a parent who only has one child.

You know what? Maybe this is part of your research. What is the difference between a parent or.. or a couple of parents who have a single child and, maybe chose just to have one child and what their parenting is like of that child, as opposed to us, who have two, but only one living and umm... I'm not sure. I feel that my parenting isn't that much different to a parent who only has one child.

Umm... And for you, the impact is different, James is.. he's always with you. He's always with you in everything you do. I think it impacts much more on your ability to trust other people with him.

C: Yeah.. And being so protective of... yeah, I mean worse for me.

J: I'm not sure whether it's much different to a parent with one child.

R: Mmm

J: I've also not known I would be a parent, obviously, as well, and whether that comes into my particular parenting or not, I.. I didn't think for a long time that I would be a parent, that I would have that opportunity of being a parent. And so when.. when it... when it came along and..

C: it was a shock

J: it was both an enormous shock to the system, but also an opportunity for me to do something which I didn't think I would have the opportunity of.

R: Mm

J: Going for a very long time in my life, and so that's another reason why I went. I was the one who went part time.. to really make the most of an opportunity that I didn't think I would have.

R: Yeah. Was that your plan with James as well? Had you thought of going part time or was that a decision after the birth of Elijah?

J: That's an interesting question. I'm not sure actually, I can't remember, because James came so early... Maybe we hadn't actually had those conversations...

C: Yeah.

J: You know, he came so early. I had to do a massive, enormous shop all of a sudden, just before he arrived, for example, and went to Mothercare, which I know isn't there anymore, that was the shop, though, and that was it.

C: That was Elijah

J: Oh ok, that was Elijah. But yeah, do you know, I don't know that we'd had.. Had those detailed conversations,

C: yeah, I think we didn't, John and I had not that long been together. We didn't think that John could have children. And so I think we pretty much well.. thought, you know, we won't.. We just won't get pregnant. So then when I did, immediately.. it was, ohhh, oh my gosh, wait a minute. We thought it wouldn't but now it will happen. So it was all... it all felt very much quite a haze, as in like, I can't believe this is happening.

J: Yeah.

C: And you know, I guess when he arrived early, I think, I don't really think we'd gotten further than knowing that I would just be on maternity leave.

R: Yeah.

J: yeah, I don't think we'd have had the conversation during..

C: I think probably in hindsight maybe... maybe with James dying.. Maybe made you realize just how very, very lucky you are. When you were thinking that you couldn't be dad for, you know, a decade or more, you know, and then obviously suddenly you are going to be a dad!

J: The opportunity opened up to me. But he's died. So I think you know that probably reinforced maybe.. the importance of being a dad. I, you know, with lots of different reasons in there as well and... Yeah, I think it. I think it definitely reinforced it was yet another reason of, you know, what we need to appreciate this time.

R: That makes sense. Are you able to describe how you feel like the loss of James has influenced your relationship with Elijah?

C: Like it's the most. It's just... Just the most precious thing in the world and.. and you know, probably more so than, you know, most mums. I feel like I probably feel that a bit more. And yeah. And you may not think that... (laughs to John)

J: I don't know. That's it. That's a really interesting question. Umm.

I suppose I don't feel like I had the opportunity to develop a relationship, a meaningful relationship, with James.

We weren't given the time to develop a meaningful relationship with him. Like we said, it was such a surprise in so many ways, and coming so early added to that feeling of 'Gosh, he's here, he's here now'.. And 'what do we do next' kind of thing. And we were at that phase.

Yeah, gosh. Wow. What, what do we do now?

C: And we didn't know we would go into. You know, it might sound really ridiculous, but we didn't know James was going to die. And you know, we thought we would be in the hospital until his due date, so we just... You know, in those first few days, we were a bit... You know, doing things here and there and you know, obviously, if we had known, we would have never left his incubator but..

J: I guess we were super anxious about Elijah when he arrived because he arrived early too, and ended up in special baby care unit as well. So that was obviously a time of incredible anxiety and yeah, and so I suppose we finally brought him home from hospital with a huge sense of relief. And I think joy.

C: But I think also, there's a photo of that, we looked at the other day of us bathing him in the hospital and my face is just... it's just complete horror and fear. But, I think in part, I couldn't believe I was taking him home, but also just so fearful of, how are we going to do this? You know, heightened so much more by, you know, we were talking the other day about it. Usually, when you leave a hospital with a baby it's very much 'Oh, my God. What do I do now? You trust me with this thing? What?', but I think for us, for me, especially, I was just... So anxious.

J: So in terms of developing of a relationship, I suppose that leads on to us... umm.. Working to form a very, very close relationship with Elijah. I guess that's what we've ultimately wanted to do.. To develop a really close attachment... Yeah... And I suppose that happens naturally to a degree. In time, most parents are able to develop a secure attachment to their child, and but maybe for us that was something that... Happened quicker. I don't know. I know. That's. I'm thinking about your question about relationship. I suppose just for me, it's just, it's very, very close and it goes with what you've said about he is the most precious thing in the world and so therefore we have a very close relationship.

Whether though, what you said about, you know, having anxiety, some things, when he goes on school trips and things, whether we've also got an an, an aspect of a fearful relationship with him, because if he were to... if anything, were to happen with him....Then I don't... Well, I don't even want to think about that. So maybe there's an element of fear in our relationship. It's not conscious. It's not there all the time. I'm not constantly afraid when I drop him off at school, not in the slightest, am I, but I suppose it might be a subconscious element of our relationship with Elijah.

R: Mmm yeah.

C: And I think, you know, we've been an intense, like, little team, you know, like a close team. And I think, you know, we're trying to balance out him being an only child by, you know, like doing very bits on the weekend, you know, like [REDACTED]. You know, but we know that it's really good for him to do things like that and I think we really try and balance... You know him having.. A lovely time with us.. A good time with us, you know, for us to have, you know, nice family time, but also for him to see and mix with other children and and I don't know, if you know, other people would do that.

You know, thinking about parents, who maybe only have one child, who've chosen to have one child, you know, would they sort of have that at the forefront of their mind? I'm I'm not really sure they would.

J: I wonder maybe also if we are a little bit more aware of the changes within him than if James had been here as well.

C: What, in terms of having two?

J: No, I think in terms of him changing and developing, I'm thinking of developmental changes. Umm. That that we notice all the time they're going on with him. Oh, gosh. Look at that. He's never said that before... He's never quite done that before... And gosh, he's nearly. He's acting like a teenager... And some little things sometimes, but we're very aware. I wonder whether we are super observant.

C: But I think also, maybe, in a way, because we've only got one child and not two to notice.

J: Yeah, yeah so maybe it's the same as parents who only have one, you will notice their changes more than if you're juggling 2 or more, I suppose.

R: Yeah.

J: Or you'd be anticipating changes if you have two, you're.. you're aware of... Well, we're aware of developmental changes and things, through our training and whatnot, but if you've already had one child who's gone through these changes, then I suppose you're expecting them because they've just happened in the younger one.

C: Yeah

J: We see them happening in our second.

C: But all of them for the first time.

J: Yeah. I don't know.

C: Yeah, which is a strange thing, isn't it? He's our second child. But we're seeing it for the first time. (*cries*)

J: Yeah. So, if you have an older one and a second one, the second one, to a degree, fits in. And I'm not saying that's always the case.

C: No, no. But people do, you know, joke about that a lot, you know, you see all sorts of little memes online and things about, you know, second child syndrome and things like that. And I'm always a bit like. (*pulls grimace*)

J: Umm, we should have that, but we... we don't.

C: Yeah, where as my second child syndrome is just anxiety riddled I guess, you know. I'd love to then be all slapdash with them and say you know, I fed you organic, and you didn't have a, you know, piece of chocolate until you were two.. And you know, with my second,

he's on what sits at 1 year old and things like that.. But I guess it's.. It's just really.. It's just really different.

R: Yeah, it is really different. It sounds like both of you really treasure your time with Elijah and try as best as you can to be as close as possible. Other than time, is there any other ways that you try to stay close?

J: Involving him in things that we do.

C: Yeah, I was just thinking he's a bit up and down with his sleep.. he's always been a bit like that. And you know, we're playing musical beds a bit. But you know, sometimes everyone needs to sleep in their own beds. But, you know, sometimes we're just 'you know what, let's go with it'. If we get a good night's sleep and one of us will stay a night in Elijah's bed.

Sometimes, I think, in terms of that physical feeling of closeness, if he's in my bed with me, I think that's actually quite nice. And I know it wouldn't last forever, because, you know, when he's a teenager he wouldn't probably want anything to do with me. Other than, you know, for money and food and things like that and I think that's a nice physical closeness. We could tie ourselves up in knots about, you know, why isn't he sleeping? And he should be sleeping in his own bed and all that. And sometimes, you know, we naturally get a bit frustrated with that. But I think sometimes, there are times where we say, 'just let him'. It's fine and and I think that is a nice closeness to have... I don't know if you'd agree on that. *(Laughs to John)*

J: Do you think some people would say he rules the roost in that respect?

C: I guess some parents might say that, but then, you know, I remember somebody once saying to me, she had taken her little one back to her bedroom and I think she'd counted and it was something like 100 times. And then she gave in and then just let her come in her bed and somebody had said to her, oh, you're making a rod for your own back. And she was very much 'But do you know what? It's my own back. It's my own rod. And I need to do what works for us'. And, you know, because let's face she could have done that 500 times in five hours and, you know, would it have really solved the problem? So I think... I do think sometimes we try... Like with the sleep thing, you know he's been a bit on and off over the years and you know, he goes through phases. But I think we try not to make a big, big deal of it. Sometimes it does get really grating you know. Last night he was still awake at 9:15. John had finished work just after 9. You know, and it does feel a bit frustrating, but I think we try and be a bit calm about it when we can.

And you know, not in terms of giving him the whole control, but I think I'm a big believer in picking our battles. I think that's always been, you know quite OK. And you know sometimes... I especially can pick them a bit better, you know, if I'm tired, cold, hungry,

then.. you know I will fly a bit more off the handle. But I think you know sometimes when I can be a bit more, 'let's just go with it', I think that does help.

J: He's very sensitive, isn't he?

C: (*laughing*) Oh, he's just like my mum, and just like me. And he always says, 'oh, I'm so sensitive'.

J: He doesn't like anyone raising the their voice at him, he will..

C: Immediately burst into tears... Yeah, he's yeah.

J: So obviously we brought him up not doing that as much as we can. Though, at moments, it becomes challenging for us, but

C: yeah, if anyone shouts, it's me and on the very rare occasion that I do, he will just collapse into a flood of tears, and then obviously I feel like I'm the worst mother in the world. But you (John) only have to raise your.. not even raising your voice, just a tiny bit, talking from one room to the other, and he is absolutely impacted by that.

J: I'm not sure if we're answering your question.

C: I don't know if we are. I forgot what the question was. (*laughs*)

R: No, no, you are, you are. It's good to have more of a conversation anyway. But you have been telling me about your relationship, you're adjusting to his needs, saying, you know, we try never to raise our voice. We do other strategies.. And so don't worry, you are answering the questions still. I've just got one more bigger question.. What do you think would have been helpful for you both after giving birth to Elijah?

C: Gosh, that is an open-ended question, I thought there was going to be another part.. Umm. That is a good question.. We had the same midwife and she was just amazing. She was just fantastic, really, really supportive.

J: She was protective of you?

C: Yeah.

J: She was Super protective of you.. Which was good. So that was really helpful. I think we needed people to protect us at that time... whether we could have done with more, I don't know. I think we had sufficient.. with her and the other key people, key support people that we have, like your mum and..

C: You know, I think it's tough. I think probably the one thing that I would have wanted was somebody to sit me down and say 'he won't die' but obviously you can't... We can't say that because actually, you know in those first few days, being in special care, you know, I guess nobody knew what would happen and you know, certainly, you know, he was so so poorly, but nobody could come and give us that cast iron 'He will be OK'. But I think that I was just

so desperate for that because I think I was just... I was just so fearful. I was just so terrified and petrified that he would die.. and I remember saying to my manager at the time when I told I was pregnant with Elijah, I remember saying I won't need the maternity leave because I think he will die. So I was so convinced. So I think if somebody could have sat me down and said he won't... But of course, how can you ever have that?

I think there's a lot to be said in terms of your hormones as a new mum, they're just crazy. How do you get that rational part of you, when you know you're overtired, you're not really eating your best, you're not firing or not cylinders, your body, you know, it's just been through utter trauma. You know, your triggered at every point of the way.

J: Do you think you got enough support at that time or not really?

C: Yeah. I mean, I think it..

J: Well, we got through it. And we're able to move on, but, it was very much just us, I suppose, for a long time.

R: Mmm

J: Perhaps I might have welcomed a bit more support, more practical support, maybe sometimes to give me some time off at times. We didn't have much time off for the first 12 months. I would have welcomed that.. A few more breaks kind of thing, more than you but I don't know.

C: Do you mean from friends and family? (To John)

Do you mean from professionals? (To R)

R: Any kind of support, professional or just anything you can think of, but yeah, that time off... what do you mean by that?

J: Ohh. From looking after Elijah I guess.

C: You needed breaks where as I probably wasn't ready for that.

J: You didn't want anything or anyone else to come in and do it. Really. And so we ended up doing most of it ourselves. Whereas, I might have welcomed that a bit. Mind you, I did train for a half marathon, so that got me out for a bit. Yeah, I did. I got a bit fitter and stuff so I was able to have breaks. But they were short ones where I did runs and things like that.

C: I think it's interesting, isn't it? Because then you know, we were talking about it..

So John assesses people who are adopting and we were talking about single parents the other day and, you know, their support network afterwards. And I would say make sure you get all your support network and tell them to do this, you know, drop a meal off on the steps, right.. Every Friday, put your ironing outside and I'll come and get that and you know, I wonder if.. and I think there's a huge cultural aspect to it, as well, I think actually parenting any baby,

whether it's a baby after a loss, or whether it's your first time or your fourth time... Maybe there could be a lot more done... By your support network in terms of, you know, dropping you something off on the doorstep, which is what we tell all of our parents to do at work and which is what we sing about 'til the cows come home in terms of supporting them and protecting them, but you know in hindsight..

J: We didn't really have it ourselves.

C: No, no. But how do you how do you ask for that?

J: We know people and we didn't accept it ourselves.

C: Well, not just accepting, but in terms of other people thinking as well.. in that I suppose maybe if we didn't know that through work, would we think to do that?

Would we have that in our mind? I think now, society's saying you have a baby and you ping back into shape, you crack on with life and stuff. Whereas, in other cultures, I read something the other day about Mums not doing anything for the first 40 days or something. And I think there is that, you know where as now, you know, if a mum's on the school run two days after giving birth, it's all magical. Where as, actually, should you be sat at home and should you have got a friend to do the school run? I don't know, I suppose what we're saying is... We could have done, in hindsight, with probably a little bit more practical support along the way.

J: And more for you than for me, though, for both of us, really.. We could probably have done with more emotional support and especially early early on when we were most vulnerable, especially you.

R: Yeah.

J: You know, some professional emotional support could have been incredibly valuable.. During the first few months, perhaps only the first few months though.

C: Yeah, only you only short term.

J: And OK you had that with the midwife, but that's only for 28 days. Post 28 days. She had to go. And we.. you missed her a lot. You missed her a lot and she didn't come that often anyway. Really.

C: No, no. But she did come a little bit

J: and she was most welcomed when she came, partly because she knew our history also. So she was really a vital person. But maybe what I'm saying is we lost her too soon.

R: Yeah.

J: Or somebody like her should have perhaps stepped in after her.

R: mm.

J: 28 days were up. Maybe we should have had access to another person to do something similar, or even just to be able to speak to... You know, they may not have had to come that often, but if she'd rung every week or something like that over the first few months, 'how are you doing? Are you OK? Is there anything you need? How are you feeling?'... That could have been greatly helpful for you, especially, but hey, for both of us also.

R: Yeah

C: But I guess it's that's not. You know, it's because of that limit of the 28 day and then you get transferred to a health visitor and you know, actually, maybe for families, you know who are bereaved... You know, maybe not just that black and white 28 days and then health is to, you know, maybe there's a bit of a... Umm... A middle gap of something that's, you know, lost in a way. Um and, you know, in terms of, you know, I've worked with um, I worked with substance misuse midwives in the past, and you know that's a really specially service and they're there and you know they're experts in their field. And I.. and I guess... Yeah, Should we have had?

J: mm maybe there's a gap there, after 28 days, there's a big gap, yeah perhaps there's a gap in the provision of emotional support, especially for people who have experienced what we did first time round or any time around.

C: Umm yeah, yeah.. Because, you know, I guess then I didn't really do baby groups. I went to a baby massage class. I met someone who has come to be, you know, one of my best friends in the world now, and her little boy is the same age as Elijah. And I think I was acutely aware that going to things like baby groups, I was readying myself for 'ohh is he your first?' 'No, he's dead'. So I always really felt quite heightened about that. And then, and interestingly, the only one group we did was the baby massage group.

I went to that because one of our friends from Sands, the neonatal death charity, we went to Sands a few months after James died and four of us mums got friendly and we all then went on to have subsequent babies and one of the ladies was having her next baby around the same time and she was going to this baby massage.. And she said, 'oh, I know somebody else who's on it'. And she knew that her daughter died. I then felt safe because, you know, I wasn't the only one with the dead baby there, and then this, the 4th person, was this lady who's now one of my best friends ever.

So, I think had I have not had that experience, I think I would have felt hugely, hugely isolated and wouldn't have really had a mum friend in a way, if I hadn't have had Helen.

J: Mm OK. Yeah, yeah.

C: And then we went on to then... What else did we do? We do, baby...Sensory.. or baby something and you know, we went on it that first.. First year or so of doing different little things and we'd go to, you know, baby library and stuff like that. But I think if I hadn't have had that and, yeah, and I think it's that whole element of, umm, post Natal care... That actually... There is real need to be specialist in terms of thinking about, you know, my, my mum's, who had substance misuse midwives, they had to be involved because there was a need, there was a clear need and.. Umm.. Well, actually, I know some people might say, 'oh, well, you know, you could think of a need for everything'. But I suppose the risks, you know, have been quite significant in terms of baby blues and post-natal depression and then, you know, awful things happening actually.

You know, and.. and then people then going on to face, you know, chronic problems of, well, you know, I felt so alone and isolated and this, that and everything else... That that then never leaves them. And you know they're not able to, you know, pair properly and then you know, the problems just sort of drip feed, don't they? But, you know, looking back in hindsight now, I think probably more specific.. and I know people will say, 'well, it's time, resources, money', but, you know, maybe something about the area that we live, you know, we aren't the only parents who are parenting after a child death. So you know, would that not be beneficial? But, of course, how do you access that? So had we have not gone to Sands, you know, how would we have?

J: No, no.

C: How you know, how would we have not then thought, you know, gosh, we're the only ones doing this because.. I mean we don't use Facebook anyway. But, of course, that would be a bit of a, you know, you look on Facebook for, you know, events and groups and things. But you know, that would be a bit of a unique thing to put on there. You know, maybe groups running for people who've experienced loss. Well, it's quite unique, isn't it? But I think we won't have been the only people so, you know, maybe a little bit of umm.. something by way of that resource, I think.... But we were really so lucky that that we found sand.

J: It was a lifesaver.

C: Yeah

J: for you. Yeah, It's especially for you

C: because Sands gave us that opportunity after James died... because I then got friendly with the four, there's four of us in total, we then all went on to have babies and... And also it was one of those mums who said 'Ohh, I'm going to the baby massage'.

C: It's quite... Is it potluck? I don't know, maybe potluck. But I'm just glad that we found Sands. But what really makes me hugely angry? And we had a terrible, terrible experience with the bereavement midwife when James died. She was hugely inappropriate and lots and lots of things went wrong. It was completely unprofessional and she didn't tell us about Sands. And I can't believe that we left the hospital at that point, you know, with nothing. We made a formal complaint and, you know, we challenged it and just, you know, very much we don't want other families to experience the same.

I just found Sands by, you know, Googling one night, during the night.. Well, what if I had not have found that? What if I'd have, you know, then been in such grips of grief and thought I can't cope. And, you know, that's, you know, people then do things like take their own life because, you know, they can't cope, where as, I can't help but think back, you know, reflection of umm.. you know, and I have, you know, the staff at the hospital saved my life and you know, I've got nothing but thanks for them and we're still in touch with some of the nurses now.

But for me, the let down of that bereavement midwife, for us, I know it might sound melodramatic, but actually she didn't give us any tools, any equipment, you know, just even a few leaflets. Well actually, I just want my baby, but to not have anything.. those leaflets would have... and maybe times have changed now, you know, maybe systems have changed and maybe that does happen now but I do think it's worrying that people who then slip through the net too maybe wouldn't have that luck of just Googling.

R: Yeah

C: And knowing how much Sands have done for us as a family, you know, in various ways, you know, during these last Seven years or so.

R: Yeah, it is lucky that you Googled, but it sounds like it would have been so helpful to have that information given to you. You've covered quite a lot of things that may be helpful...

You've mentioned professionals involved knowing your history and being there for you after Elijah was born, someone that's willing to protect you both.

And when you said that the really good midwife was protective, how did she do that? What did she do that made you think she's protecting you?

C: I guess, I guess, her demeanour, her manner, her care, her kindness.

R: OK.

J: I think she was looking out for you and making sure that you hadn't, you know, developed the symptoms of post-natal depression, for example, which could have been very possible after Elijah. So I suppose professionally she was keeping an eye on you for that.

R: Yeah.

J: From that point of view, which was absolutely essential, obviously, but part of the role after she did that, she did much more in terms of, like, befriending, I guess.

R: mmm

J: And being accessible and she.. yeah, she was a person who was there and available if we, you know, if we needed.

R: Yeah

J: I suppose the other person who was called for us was our GP actually. And he knew, obviously, of James beforehand, so he's inevitably good. Was he linked to the midwife?

C: No, he was good though. Yeah. I know doctors get, you know, bad names in terms of where you go and you see a different one every time and you know you never know who you go and see and things But yeah, with me, he was really, really kind and supportive and you know, we had various bits that, you know, we saw him for, you know, both together. And after James died and then I had some time off sick post maternity leave from Elijah too when I then went back to work because I was, I was really struggling.

J: You were very much supported by him.

C: Yeah, he was hugely supportive. Yeah, really, really, really kind, you know, in a way that it didn't feel, you know, that you were just sort of shipped in and shipped out.

J: You were able to access him as many times as you needed without questions, wasn't it? He was guided by you in in a way.

R: Good, good. And you also mentioned emotional support from professionals would have been helpful after the 28 days as well.. And maybe more practical support from friends and family, bringing meals in, things like that..

C: Yeah, I think so. Yeah. Yeah. Yeah. And you can't really ask for it at the time. And it's funny, isn't it? Because it's just entirely, you know, what we spout at work in terms of self-care and support network and all that. But when it's you, I think I struggle to ask for help. I think you feel like, you know, you just need to crack on. I think it's really hard that we haven't got any family nearby whatsoever. And you know, it might feel a bit easier to ask family. It's hard. I think it's hard to ask, isn't it?

J: I think for you it's hard. Yeah, I might have asked more, but... Yeah, I guess you actually didn't really want to ask. But then I guess you were in that balance between, you know, you couldn't possibly face just leaving Elijah's side.

C: whereas you were 'Oh, my gosh, we need a break'. And I just couldn't do that. So yeah, you know, I guess.

J: Yeah, we muddled through. We were OK.

R: Yeah. And is there anything else I haven't asked you about, or that we haven't covered that you think would be helpful or want to mention?

C: um... no I don't think so, I think it's just, this strengthening of the links with umm bereavement support upon leaving hospital because I think you know the outcomes there could be really dire and and I think.. I really hope that in seven years things have changed. But I think you know the system that that was in place for us just, there was no safety net whatsoever and I I just feel like that is completely unacceptable.

R: mm

J: Do you mean after Elijah or after James died?

C: No. Well, no. When James died in the, you know, I only found the umm Sands thing by luck, you know, the bereavement midwife there should have come to see us.. Should have status down and said.. You know, even things like.. James, you know when James died and you know, obviously, you know, he deteriorated, and, you know, in terms of appearance and things, you know, there was nobody to have those conversations with us and I think, you know all of that, combined, you know, combined with, you know, little bits of leaflets and and things for people like Sands would have been really helpful. Um, and then I think, you know, with James, I think it's definitely about that gap in between, you know, most mums probably are quite happy at that 28 day handover of um, you know you get moved on to the health visitor naturally, you know, most people probably don't have all that much to do with the health visitor so it's, you know, I think that's how it is, but yeah.. And I think on on reflection, there was maybe a gap that we fell through because... The anxiety was still there. It it didn't just go away after having that 28 day period of of, you know, midwifery support um yeah, I think there's, you know um, whether that is the specialist midwife team that you know, work for a little bit longer or whether that's, you know, a specialist it's health visitor who is, you know, the bereavement specialist who works with families who have experienced loss and visits a bit more in those early days.

J: Maybe it shouldn't be 28 days for parents who have lost a child.

C: Yeah

J: maybe that that, you know, our case that that should be extended, that 28 days should naturally be extended, so therefore it's the same person we're seeing who's known us.

C: You know, to something almost like six months. You know, I almost think..

J: Gosh, you think as long as that?

C: yeah, I almost think, you know, and I know people would say, well, if not, you know, we've not got enough people do that, but I think, yeah, that's six, six months, definitely. And you know, maybe, you know, more intensive for the first three months and than that you know, second lot of three months. But yeah, there's there's definitely you know, because the the consequences, you know, if somebody falls down a dark hole and cannot get themselves out of that dark hole and then think, right, you know, baby and I can't live.. You know, if you think about the worst possible case scenario, that's, you know, it's not just, you know, someone might be a little bit fed up and you know, yeah, you know, the the outcomes are absolutely, you know, dire and I think you know particularly for people's relationships as well. I mean, you know, sometimes I think goodness knows how we've coped in terms of relationship um you know, because a lot of people don't make it after the..

J: Yes, it's so it's so it's not just you (*Mum*) who were vulnerable in those first few months, we both were vulnerable, as was perhaps our relationship in some respects because it was being severely severely tested.

R: Yeah.

J: You know, we were vulnerable but the the the care disappeared very quickly. An oversight even.

R: And was it are you referring to after Elijah was born?

J: Oh yes, that's right. Yeah. Yeah, absolutely. Yeah. Yeah, yeah.

R: Yeah ok

C: I mean, even after James.

J: Yeah, we were similarly, but we were more looked after by our GP at that point.

C: Yeah. And I suppose with Elijah, we had not only our relationship to contend with, but a new born to look after whilst you know, still very much in the midst of grief and parenting a first time you know

J: Mm parenting for the first time.

C: Yeah, you know, what what's that? What does that cough mean?

J: We were, we had multiple vulnerabilities at the time.

C: If you think of the equivalent of ACES, we were up there in terms of, you know, those risks. And I suppose that's when people's relationships quite often deteriorate because, you know, stereotypically, you know, male and females manage and cope with grief in very different ways, so um you know if people then think the other person, Ohh you don't care, you're not bothered. You know that's when gaps then start to occur and..

J: Tension..

C: Yeah. Yeah. And I suppose, you know the foundation of our life then, you know, if that goes under, then you know my risk, you know, if I'd have then been on my own with Elijah, my risk factors then become even higher because you know, we're not a two-parent household. It's somebody who's, you know, got an an additional..

J: We were never close to this

C: But no, no

J: Sorry

C: no, no, not at all

J: We never got anywhere near

C: No, never, but for some families, I guess that's the risk, that's a risk, isn't it? And you know, and that risk is heightened by their not being that bridged that gap being bridged of that service.

R: Yeah, there's definitely a lot to think about, isn't there? Umm yeah.... I guess that that's all of my kind of questions out the way. So thank you so so much for your time and for answering them with me um, what I'll do is send that signposting information sheet to you again just in case, you know, you've thought of anything and you want any more support.

C: Yeah, that's OK. But if you need to send it, that's fine. Thank you.

J: Yeah, that yeah, yeah.

R: Yeah, yeah, I'll just send it in an e-mail so you've definitely got it. You don't have to use it, but it's there if you want it.

C: Yeah.

R: And yeah, if you've got any questions feel free to ask, or if anything comes up later, because sometimes when you're put on the spot, it's hard to think, so feel free to e-mail me, that's fine.. But otherwise, I just want to thank you so, so much for your time. And I know it can be an emotive topic, so look after yourselves, make yourself a cup of tea. And I hope you've got something nice planned in for today, aside from the football later.

J: Thank you. I found it helpful myself and quite therapeutic to think like this actually. It's been healthy, it's been helpful because obviously we don't talk like this, we're not asked questions like this very much. But I think it can be quite a therapeutic thing to do so no, thank you for the opportunity to be able to do that.

C: Yeah. Yeah. Thank you.

R: You're so welcome.

C: It's not often that you get to talk about, you know, your baby who's who's died. And then, yeah, I think it's really helpful. And I don't know why I'm so emotional. You wouldn't think a

few weeks ago, Elijah and I were raising awareness, and, you know, I was talking about Elijah and James for charity. And I was really like, together and, you know, yeah, but, I I don't know why I don't.. I haven't felt right this morning. But yeah, there's not really an opportunity to talk much about each child who's died. So I think it's a.. It's definitely helpful. So yeah, thank you.

R: No, no problem. Thank you.

C: Ohh well I just hope that, yeah, the research helps and I think it would be really interesting, you know, do you send the outcome to people? Like I know it might be like a long time but it would be lovely to read it.

R: it's a long old process but of course, I am happy to send it to you.

C: Absolutely, yeah. Yeah. Well, I was thinking in, you know, a couple of years maybe when you're done or even more, I don't know. But yeah, it'd be lovely to see.

R: So what happens is I write up a really long version for part of my doctorate course and then we hopefully condense it down to something that hopefully is publishable. And if you're interested, I can keep your e-mail and send either version on to you.

C: Well, for sure, I think that absolutely, yeah, the published version or not published version. I mean how could it not be published in terms of, you know, it's just so unique, isn't it, you know, and a taboo, you know? Elijah's head teacher said the other day, you know, after we'd spoken about it, it's a taboo, isn't it? And people don't know what to say. And yeah.

R: Yeah.

C: I think it's a really.. I'm glad that you've done it. It would be really interesting to see and I did think, as well, I might mention to my Sands friends, because, you know, it might be something they might be happy to speak with you and I don't know if you've got enough people now or not. You know, have you got enough?

R: Thank you, that's really kind. I hopefully have enough, but if I get stuck and I e-mail you, would that be alright?

C: Yeah, yeah, absolutely. I just think that's three people there. And even if one of them said, but yeah, they might. You know, yeah, I mean, equally. They might have already just I think I saw on... I can't remember it's Twitter or it might have been Instagram. So you never know, you might have them on your list if they've seen it, but yeah... If you're, if you're low on numbers and you need them, you need to e-mail me, that's fine.

R: Thank you.

C: You're welcome.

R: That's lovely. Thank you. And I'll hold on to your e-mail so that eventually I'll send you the research. Thank you so much for your time. You both take care of yourselves.

J: Thank you. You take care. Bye bye.

C: Bye and good luck.

R: Thank you so much. Take care.

C: Thank you. Bye bye.

Appendix I. Example of Data Analysis

Agreed (more appreciation)

33 M: **very much so**. But yeah, it was it, I was self employed by
 34 time We had Alana so I had cut back on my work time a lot
 35 more. I'm back in work full time now *M laughs* umm but
 36 I'm much **more confident now that it will be OK**. *needed lots of reassurance at first
 worried something will happen to
 rainbow child.*

37 R: Mm, what do you think happened? When was that shift?
 38 M: Umm, I think once she **stopped looking so much like a**
 39 **baby**. Umm once she started walking and talking and *Gets easier to separate narratives
 /children*
 40 becoming a person, if that make.. I'm not saying babies
 41 aren't people, but you watch them grow and develop their
 42 personality and start to become who they are. Umm.. And I
 43 think it was a sort of a slow shift with that because Ciara will *Baby that died stuck in time*
 44 **always be a baby**. Ciara was the baby that we lost.. So the
 45 further away Alana gets from that stage, the greater the
 46 **separation...** for for us, if that makes sense. *Danger zone.*

47 R: Yeah, that does make sense.
 48 J: Yeah, I mean, it hasn't really changed for me.. *Dads feelings haven't shifted in same
 way as mums.*

49 M: Yeah you're **different** to me. You're you're different to *Differently affected*
 50 me.
 51 J: Yeah, I still.. Yeah.. Still feel the same? I still feel the same. *Hasn't gotten easier for dad,*
 52 Like my feelings about Alana are still the same. I still sort of
 53 interact and spend time in the same way that I did from the
 54 start, really.. just a bit, a bit less time. *lots of humour in this interview
 ↳ what's the performative function?
 Covering shame? sadness?*

55 M: You're a nicer person than me though. (*M laughing*)
 56 R: So are you saying that you still worry the same?
 57 J: Yeah. Yeah, definitely. Yeah, I still sort of like, I have done *Dad unafraid to talk about
 worry*
 58 the same with Sian, um ever, ever since ever since we lost
 59 Ciara... But of the sort of I'll just go and **make sure that she's** *checking*
 60 **still breathing, even though there's, like, literally no reason** *need re-assurance.*
 61 **why she shouldn't be...** And if she's like, playing or **quiet for** *able to rationalize but still checks.*
 62 a while, and I always make sure that I'm going to **check as** *quiet uneasy - reminder of loss*
 63 well just to make sure that everything's OK and probably did

→ Different to parenting before loss.

- 64 that a little bit less with Sian, and I think and we're still,
 65 we're still quite aware I think? → More aware of risk. / what can go wrong.
 66 M: Yeah.
 67 J: But there was less of less of that, I think.. more just that
 68 sort of banal assumption that everything will be OK as → Previous bubble of ignorant bliss
 ↳ loss burst bubble.
 69 opposed to knowing that there is a possibility that it might
 70 not. → Risk is very real. Bad things happen!
 71 M: Yeah, I think I've sort of deliberately tried to let go of that → Coping
 72 because I know, although there is always the possibility that → Risk awareness
 73 something could happen, I don't want to live with those Mum more resigned to possibility
 74 thoughts. ↳ choice of risk consciousness. conscious effort
 75 J: Yeah. not to think of risk.
 76 M: So I don't know if I make a concerted effort to just put
 77 them to one side and. *pause* ↳ co-construction
 78 J: Yeah. I think for me like I am.. having having experienced
 79 it once, I sort of, it's just really difficult to know how to → Choosing wording for
 80 describe it appropriately, but I suppose it just makes me feel audience.
 81 like, you know, if anything, what happened again that we → we've been through the worst,
 82 would be able to deal with it. Again, this is a weird sort of, we can handle anything
 83 you know, the knowledge of how bad things were... It's like → making meaning of loss.
 84 a reassurance that, like, we're not just us, but just as human → masculine need for story of
 85 beings we are a lot stronger, I think than perhaps we realize, strength to balance worry(?)
 86 yeah. ↳ more stumbling/hesitations ↳ A story of resilience emerging
 87 M: Yeah. ↳ uncomfortable to talk about positive from baby loss(?)
 88 J: But a lot of that's like the confrontation, isn't it? Of like Dad needing to confront difficult
 89 working hard on confronting those feelings. I think that's, feelings. ↳ Navigating parenting
 ↳ grief.
 90 you know, obviously everyone, everyone deals with these
 91 things and processes them in their own way, but there
 92 comes a time I think where in order to heal and move
 93 forward, you have to confront a lot of those feelings,
 94 because otherwise you can just get stuck. ↳ 'stuck' on grief/baby loss
 95 MJ Yeah, they're not nice things to have. ↳ understatement? Performance of coping?
 ↳ Making story easier for audience?

Appendix J. Ethical Approval

Decision - Ethics ETH2122-1292: Miss Georgia Smith



⊗ ERAMS <erams@essex.ac.uk>

To: ⊗ Smith, Georgia

University of Essex ERAMS

29/09/2022

Miss Georgia Smith

Health and Social Care

University of Essex

Dear Georgia,

Ethics Committee Decision

Application: ETH2122-1292

We are pleased to inform you that the research proposal entitled "Couple's experiences of parenting a pre-adolescent child following perinatal loss" has been reviewed by the Ethics Sub Committee 2, and, based on the information provided, it has been awarded a favourable opinion.